

DEPARTMENTS OF LABOR, HEALTH AND HUMAN SERVICES, AND EDUCATION, AND RELATED AGENCIES APPROPRIATIONS FOR FISCAL YEAR 2012

U.S. SENATE,
SUBCOMMITTEE OF THE COMMITTEE ON APPROPRIATIONS,
Washington, DC.

[CLERK'S NOTE.—The subcommittee was unable to hold hearings on departmental and nondepartmental witnesses. The statements and letters of those submitting written testimony are as follows:]

DEPARTMENTAL WITNESSES

PREPARED STATEMENT OF THE CORPORATION FOR PUBLIC BROADCASTING

Chairman Harkin, Ranking Member Shelby, and members of the subcommittee, thank you for allowing me to submit testimony on behalf of our Nation's public media system.

Every day across the country, people turn to public radio and television for programs that inform and inspire; for lifelong education; for local news and information; for arts and cultural content, and for a variety of other services. Public broadcasting, or what should more accurately be called "public media," has many faces, and employs around 24,000 people, but is best-known by the 1,300 local public radio and television stations across the country that provide unique local service to their communities. These stations collectively reach more than 98 percent of the U.S. population with free, over-the-air television and radio programming and other services. When Congress appropriates money to the Corporation for Public Broadcasting (CPB), it is benefitting the 170 million Americans who use public broadcasting each month by supporting the stations that serve them.

CPB distributes Federal funds in accordance with a statutory formula contained in the Public Broadcasting Act of 1967, under which more than 70 percent of our funds go directly to local public television and radio stations. CPB also supports the creation of programming for radio, television, and digital media. The statute ensures diversity in this programming by requiring CPB to fund independent and minority producers. CPB fulfills these obligations by funding the Independent Television Service and the five Minority Consortia in television (which represent African American, Latino, Asian American, Native American, and Pacific Islander producers) and similar organizations in radio. CPB funds the National Program Service at PBS, which supports signature programs like "PBS NewsHour", "NOVA" and "American Experience"; as well as educational, scientifically researched, impactful and trusted children's programming like "Sesame Street", "Curious George", and "Word Girl".

In addition, CPB spends 6 percent of its funds on projects that benefit the entire public broadcasting community, befitting its role as the only entity responsible for and answerable to the entirety of the public media system. CPB negotiates and pays music royalties for all of public broadcasting, for example, and funds research to explore audience needs and technological opportunities. Added together, these efforts account for 95 percent of the funds appropriated to CPB (which is limited by law to an administrative budget of no more than 5 percent).

Some have suggested that public broadcasting can easily do without Federal funding. Let me briefly explain the critical importance of Federal funding to public media as it exists today, and what the impact would be if it were to go away. Congress designed the public media system in this country as a public-private partner-

ship, where minimal Federal dollars are leveraged to the maximum extent to ensure universal service to every American and every community. While CPB's appropriation accounts for around 15 percent of the entire cost of public broadcasting, this "lifeblood" funding leverages critical investments from State and local governments, universities, businesses, foundations and from viewers and listeners of local stations. Put simply, CPB funding is the foundation on which the entire system is built. Undermining the foundation puts the entire structure in jeopardy.

CPB funding is particularly important to minority-owned public stations and stations in rural areas, which are more challenging to operate due to low population density of viewers and listeners; the need to operate multiple transmitters to reach far-flung populations; and the limited disposable incomes and potential for private support often found in rural America. In fiscal year 2009, individual donations represented 17 percent of an average rural station's total revenue, versus almost 28 percent for the industry as a whole. The disproportional importance of Federal funding to stations in rural areas is clear—in fiscal year 2009, 108 rural stations relied on CPB for at least 25 percent of their revenue; while 22 rural stations, many on Native American reservations, relied on CPB funding for at least 50 percent of their revenue.

Finally, CPB funding is also the only funding source without a station cost associated with it—all other fundraising costs money (for stations and for any nonprofit). For example, in fiscal year 2008 it costs the average station 40 cents on the dollar to raise funds from individuals and local businesses.

Numerous studies, including one conducted by the Government Accountability Office (GAO), have shown that the loss of Federal funding would create a void not easily filled by other sources of funding. For the vast majority of stations, this would mean a drastic and immediate cutback in service, local programming and personnel, and in many cases stations would "go dark." Further, the loss of Federal funding would have a severe impact on a station's ability to acquire national programming, such as "The Electric Company", "Super Why!", "NOVA", "American Experience", "Frontline", "PBS NewsHour", Marketplace and many others, from PBS, NPR, American Public Media and other sources. Federal funding has been the basis for this highly successful public media model since CPB was created nearly 45 years ago. Without it, public media ceases to exist as its creators intended.

Core System Support

One of CPB's core responsibilities is to preserve, protect, and advance public media. Public television and radio stations are facing an unprecedented array of challenges. These include the challenging economy, reductions in Federal and State support, shifting community demographics, fracturing audiences and emerging patterns in the way content is delivered and consumed. Public television has been hit especially hard. Over the past two years, the public television economy has declined by \$250 million, and CPB projects a further \$250 million decline over the next two years. In addition, while the digital conversion in public television has provided exciting new opportunities for service, digital equipment becomes obsolete much more quickly than the analog equipment it replaced. The more or less constant cost of equipment replacement is further affecting public television. To cope with declining revenue and increasing equipment expenses, many stations have been forced to cut local service. As a result, the need to maintain infrastructure is draining resources from content and local service at stations.

CPB is working in two areas to help the system begin to facilitate collaboration and operational efficiencies: mergers and consolidations, and joint master control operations.

Mergers and Consolidation.—Most communities are served by one or more stand-alone public broadcasting stations. While independent local stations theoretically have a great deal of flexibility in choosing how to serve their community, the limited scale of many stand-alone operations drives up operating costs and constrains stations' ability to offer local service.

State networks like Iowa Public Television and Alabama Public Television have demonstrated the advantage of taking an alternative approach. Combining management and back office operations to serve multiple communities can increase efficiency and free resources for additional local service. CPB plans to continue to work with stations to explore operating models that bring multiple stations together as an important focus of our work. Our efforts include offering informal advice to stations considering mergers and, once stations issue a formal intent to merge, providing some financial assistance with merger-related costs.

Central Master Control.—A master control room is the central hub of a television station's technical operation, the point where content sources come together to be routed to the station transmitter. In the past, each television station has needed a

master control room. Digital technology now allows the master control function to be provided from a remote location. A single master control facility can now serve multiple stations. This is important because master controls are expensive; they are both capital- and people-intensive. Combining master control operations can yield significant cost savings, increase productivity, and encourage station collaboration in other back-office areas.

CPB is supporting the design and construction of multi-station master control facilities. We are also exploring the practicality of creating a nationwide “master plan” for master control facilities. As the specifics of a new consolidated master control function evolve, there is an opportunity to realize cost savings, reduce the capital burden on stations, and improve efficiency for public television.

American Graduate

In the words of our statute, “[I]t is in the public interest to encourage . . . the use of [public] media for instructional, educational, and cultural purposes.” Education continues to be a core value of the public broadcasting community, as it has been since its inception. For over 40 years, public broadcasting stations have made a robust and vital contribution to education and an informed and strengthened civil society, and these contributions are reflected in CPB’s recently-launched American Graduate initiative.

American Graduate is a significant new public media initiative to help improve our Nation’s high school graduation rates. Every year, more than 1 million students drop out of high school. If that trend continues, over the next 10 years, it will cost the Nation more than \$3 trillion in lost wages, productivity and taxes. American Graduate expands on public media’s record of success in early childhood education to reach students in middle school—a critical point when the disengagement that leads to dropping out in high school often begins. Local public radio and television stations are at the core of this initiative and are uniquely positioned to educate and engage various stakeholders on the dropout problem, rally support and help coordinate efforts in communities, something experts say is crucial to a solution.

CPB’s Requests for Appropriations

Public media stations continue to evolve, both operationally and more importantly in the myriad ways they serve their communities. Stations are committed to reaching viewers and listeners on whatever platform they use—from smart phones to iPads to radios to television sets. While stations can and will continue to adapt and thrive in the digital age, without sufficient support they cannot provide service on evolving platforms. As the Federal Communications Commission’s National Broadband Plan noted, “Today, public media is at a crossroads . . . [it] must continue expanding beyond its original broadcast-based mission to form the core of a broader new public media network that better serves the new multi-platform information needs of America. To achieve these important expansions, public media will require additional funding.”

CPB Base Appropriation (Fiscal Year 2014).—CPB has requested a \$495 million advance appropriation for fiscal year 2014, to be spent in accordance with the Public Broadcasting Act’s funding formula. The two-year advance appropriation for public broadcasting, in place since 1976, is the most important part of the “firewall” that Congress constructed between Federal funding and the programs that appear on public television and radio. President Gerald Ford, who initially proposed a 5-year advance appropriation for CPB, said it best when he said that advance funding “is a constructive approach to the sensitive relationship between Federal funding and freedom of expression. It would eliminate the scrutiny of programming that could be associated with the normal budgetary and appropriations processes of the government.”

Our fiscal year 2014 request balances the fiscal reality facing our Nation with the stark fact that stations are struggling to maintain service to their communities in the face of shrinking non-Federal revenues—a \$218 million, or 9.2 percent, drop between fiscal year 2008 and 2009 alone. Even with these challenges, public broadcasting contributes to American society in many ways that are worthy of greater Federal investment. In fiscal year 2014, CPB will continue to support a range of programming and initiatives through which stations provide a valuable and trusted service to millions of Americans.

CPB Digital Funding (Fiscal Year 2012).—CPB requests \$48 million for CPB Digital for fiscal year 2012, \$11.5 million less than requested in fiscal year 2011. The digital conversion of public media is a much more extensive process than simply replacing analog with digital equipment. Digital conversion requires the development of new organizational models optimized for the digital environment, with new workflows, multi-channel services, and multi-platform distribution. CPB Digital

funding, which can fund a wider range of projects than our formula-governed main account, has led to some of the most important innovation in public broadcasting's history. The continuing availability of this funding is critical to public broadcasting's progress toward a true, digital public service media.

Ready To Learn (Fiscal Year 2012).—CPB requests that the U.S. Department of Education's Ready To Learn (RTL) program be funded at \$27.3 million, the same level as fiscal year 2011. A partnership between the Department, CPB, PBS and local public television stations, RTL leverages the power of digital television technology, the Internet, gaming platforms and other media to help millions of young children learn the reading and math skills they need to succeed in school. The partnership's work over the past few years has demonstrably increased reading scores particularly among low-income children and has erased the performance gap between children from low-income households and their more affluent peers. An appropriation of \$27.3 million in fiscal year 2012 will enable RTL to develop tools to improve children's performance in math as well as reading and bring on-the-ground, station-convened early learning activities to more communities.

All told, the Federal contribution to public media through CPB amounts to \$1.39 per American per year and, in a model private-public partnership, the public media system takes each of these dollars and raises six dollars more. The returns for taxpayers are exponential. They include in-depth news and public affairs programming on the local, State, national and international level; unmatched, commercial-free children's programming; formal and informal educational instruction for all ages; and inspiring arts and cultural content.

Mr. Chairman and Ranking Member, thank you again for allowing CPB to submit this testimony. We are under no illusions about the pressures you face on a daily basis as Congress works to address our country's perilous fiscal situation. As such, on behalf of the public broadcasting community, including the stations in your states and those they serve, we sincerely appreciate your support.

PREPARED STATEMENT OF THE RAILROAD RETIREMENT BOARD

We are pleased to present the following information to support the Railroad Retirement Board's (RRB) fiscal year 2012 budget request.

The RRB administers comprehensive retirement/survivor and unemployment/sickness insurance benefit programs for railroad workers and their families under the Railroad Retirement and Railroad Unemployment Insurance Acts. The RRB also has administrative responsibilities under the Social Security Act for certain benefit payments and Medicare coverage for railroad workers. During the past 2 years, the RRB has also administered special economic recovery payments and extended unemployment benefits under the American Recovery and Reinvestment Act of 2009 (Public Law 111-5). More recently, we have administered extended unemployment benefits under the Worker, Homeownership, and Business Assistance Act of 2009 (Public Law 111-92), and the Tax Relief, Unemployment Insurance Reauthorization, and Job Creation Act of 2010 (Public Law 111-312).

During fiscal year 2010, the RRB paid \$10.8 billion, net of recoveries, in retirement/survivor benefits to about 582,000 beneficiaries. We also paid \$156.3 million in net unemployment/sickness insurance benefits to some 38,000 claimants. Unemployment benefits included \$19.4 million under Public Law 111-92, and about \$0.8 million under Public Law 111-5. In addition, the RRB paid benefits on behalf of the Social Security Administration amounting to \$1.3 billion to about 116,000 beneficiaries.

PROPOSED FUNDING FOR AGENCY ADMINISTRATION

The President's proposed budget would provide \$112,239,000 for agency operations, which would enable us to maintain a staffing level of 902 full-time equivalent staff years (FTEs) in 2012. The proposed budget would also provide \$1,810,000 for information technology (IT) investments. This includes \$700,000 for costs related to systems modernization and e-Government, and \$654,000 for improvements related to cyber security and continuity of operations. The remaining \$456,000 would be used for network operations, infrastructure replacement and emergency restoration services.

AGENCY STAFFING

The RRB's dedicated and experienced workforce is the foundation for our tradition of excellence in customer service and satisfaction. Like many Federal agencies, however, the RRB has a number of employees at or near retirement age. Nearly 70 per-

cent of our employees have 20 or more years of service at the agency, and about 40 percent of our current workforce will be eligible for retirement by January 1, 2013. To help prepare for the expected staff turnover in the near future, we are placing increased emphasis on strategic management of human capital. Our human capital plans provide for employee support and knowledge transfer, which will enable the RRB to continue achieving its mission. In addition, with the agency's formal human capital plan, succession plan and various action plans in place, we are ensuring that succession management supports a systematic approach to ensuring a continuous supply of the best talent through helping individuals develop to their full potential.

In connection with these workforce planning efforts, our budget request includes a legislative proposal to enable the RRB to utilize various hiring authorities available to other Federal agencies. Section 7(b)(9) of the Railroad Retirement Act contains language requiring that all employees of the RRB, except for one assistant for each Board Member, must be hired under the competitive civil service. We propose to eliminate this requirement, thereby enabling the RRB to use various hiring authorities offered by the Office of Personnel Management.

INFORMATION TECHNOLOGY IMPROVEMENTS

We are actively pursuing further automation and modernization of the RRB's various processing systems to support the agency's mission to administer benefit programs for railroad workers and their families. Key capital initiatives for fiscal year 2012 include projects to add new reporting services to our Employer Reporting System, and to continue with long-term system modernization efforts. In recent years, the agency has moved to a relational database environment and optimized the data that reside in the legacy databases. In fiscal year 2012, our staff will work with an experienced DB2 Database Administrator to ensure that the master database remains platform independent and to develop stored procedures that will be used by reengineered mainframe programs that access the master database. We also plan to move forward with reengineering the applications to the agency's LAN enterprise program platform, several of which are programmed in outdated, commercially unsupported technologies.

Our budget request also provides for cyber security improvements to ensure that the RRB continues to control the risks that threaten the agency's critical assets and to meet the security requirements set forth in the Federal Information Security Management Act (FISMA) of 2002, and infrastructure investments to maintain our operational readiness and provide a firm foundation for our target enterprise architecture.

OTHER REQUESTED FUNDING

The President's proposed budget includes \$51 million to fund the continuing phase-out of vested dual benefits, plus a 2 percent contingency reserve, \$1,020,000, which "shall be available proportional to the amount by which the product of recipients and the average benefit received exceeds the amount available for payment of vested dual benefits." In addition, the President's proposed budget includes \$150,000 for interest related to uncashed railroad retirement checks.

FINANCIAL STATUS OF THE TRUST FUNDS

Railroad Retirement Accounts.—The RRB continues to coordinate its activities with the National Railroad Retirement Investment Trust (Trust), which was established by the Railroad Retirement and Survivors' Improvement Act of 2001 (RRSIA) to manage and invest railroad retirement assets. Pursuant to the RRSIA, the RRB has transferred a total of \$21.276 billion to the Trust. All of these transfers were made in fiscal years 2002 through 2004. The Trust has invested the transferred funds, and the results of these investments are reported to the RRB and posted periodically on the RRB's website. The net asset value of Trust-managed assets on September 30, 2010, was approximately \$23.8 billion, an increase of \$0.5 billion from the previous year. As of April 2011, the Trust had transferred approximately \$11 billion to the Railroad Retirement Board for payment of railroad retirement benefits.

In June 2010, we released the annual report on the railroad retirement system required by Section 22 of the Railroad Retirement Act of 1974, and Section 502 of the Railroad Retirement Solvency Act of 1983. The report addressed the 25-year period 2010–2034, and included projections of the status of the retirement trust funds under three employment assumptions. These indicated that barring a sudden, unanticipated, large decrease in railroad employment or substantial investment losses, the railroad retirement system would experience no cash flow problems for the next

23 years. Even under the most pessimistic assumption, the cash flow problems would not occur until the year 2033. The report did not recommend any change in the rate of tax imposed by current law on employers and employees.

Railroad Unemployment Insurance Account.—The RRB's latest annual report on the financial status of the railroad unemployment insurance system was issued in June 2010. The report indicated that even as maximum daily benefit rates rise 39 percent (from \$64 to \$89) from 2009 to 2020, experience-based contribution rates are expected to keep the unemployment insurance system solvent, except for small, short-term cash-flow problems in 2010 and 2011. Projections show a quick repayment of loans even under the most pessimistic assumption.

Unemployment levels are the single most significant factor affecting the financial status of the railroad unemployment insurance system. However, the system's experience-rating provisions, which adjust contribution rates for changing benefit levels, and its surcharge trigger for maintaining a minimum balance, help to ensure financial stability in the event of adverse economic conditions. No financing changes were recommended at this time by the report.

Due to the increased level of unemployment insurance payments during fiscal years 2009 and 2010, loans from the Railroad Retirement (RR) Account to the RUI Account became necessary beginning in December 2009. The balance of loans from the RR Account was \$47.4 million at the end of fiscal year 2010, including \$0.9 million in accrued interest. The estimated loan balance at the end of fiscal year 2011, is \$3.0 million, and full repayment of the loans is expected during fiscal year 2012.

Thank you for your consideration of our budget request. We will be happy to provide further information in response to any questions you may have.

PREPARED STATEMENT OF THE INSPECTOR GENERAL, RAILROAD RETIREMENT BOARD

My name is Martin J. Dickman and I am the Inspector General for the Railroad Retirement Board. I would like to thank you, Mr. Chairman, and the members of the Subcommittee for your continued support of the Office of Inspector General.

BUDGET REQUEST

I wish to inform you of our fiscal year 2012 appropriations request and describe our planned activities. The Office of Inspector General (OIG) respectfully requests funding in the amount of \$9,259,000 to ensure the continuation of its independent oversight of the Railroad Retirement Board (RRB). During fiscal year 2012, the OIG will focus on areas affecting program performance; the efficiency and effectiveness of agency operations; and areas of potential fraud, waste and abuse.

OPERATIONAL COMPONENTS

The OIG has three operational components: the immediate Office of the Inspector General, the Office of Audit (OA), and the Office of Investigations (OI). The OIG conducts operations from several locations: the RRB's headquarters in Chicago, Illinois; an investigative field office in Philadelphia, Pennsylvania; and five domicile investigative offices located in Arlington, Virginia; Houston, Texas; San Diego, California; Miami, Florida; and New York, New York. These domicile offices provide more effective and efficient coordination with other Inspector General offices and traditional law enforcement agencies with which the OIG works joint investigations.

OFFICE OF AUDIT

The mission of the Office of Audit is to promote economy, efficiency, and effectiveness in the administration of RRB programs and detect and prevent fraud and abuse in such programs. To accomplish its mission, OA conducts financial, performance, and compliance audits and evaluations of RRB programs. In addition, OA develops the OIG's response to audit-related requirements and requests for information.

During fiscal year 2012, OA will focus on areas affecting program performance; the efficiency and effectiveness of agency operations; and areas of potential fraud, waste, and abuse. OA will continue its emphasis on long-term systemic problems and solutions, and will address major issues that affect the RRB's service to rail beneficiaries and their families. OA has identified four broad areas of potential audit coverage: Financial Accountability; Railroad Retirement Act & Railroad Unemployment Insurance Act Benefit Program Operations; Railroad Medicare Program Operations; and Security, Privacy, and Information Management.

During fiscal year 2012, OA must accomplish the following mandated activities with its own staff: Audit of the RRB's financial statements pursuant to the require-

ments of the Accountability of Tax Dollars Act of 2002 and evaluation of information security pursuant to the Federal Information Security Management Act (FISMA).

During fiscal year 2012, OA will complete the audit of the RRB's fiscal year 2011 financial statements and begin its audit of the agency's fiscal year 2012 financial statements. OA contracts with a consulting actuary for technical assistance in auditing the RRB's "Statement of Social Insurance", which became basic financial information effective in fiscal year 2006. In addition to performing the annual evaluation of information security, OA also conducts audits of individual computer application systems which are required to support the annual FISMA evaluation. Our work in this area is targeted toward the identification and elimination of security deficiencies and system vulnerabilities, including controls over sensitive personally identifiable information. OA will also conduct an audit of employer compliance with the provisions of the Railroad Retirement and Railroad Unemployment Insurance Acts. Our work in this area is designed to verify the completeness and accuracy of the external reviews performed by the RRB's compliance group.

OA undertakes additional projects with the objective of allocating available audit resources to areas in which they will have the greatest value. In making that determination, OA considers staff availability, current trends in management, Congressional and Presidential concerns.

OFFICE OF INVESTIGATIONS

The Office of Investigations (OI) focuses its efforts on identifying, investigating, and presenting cases for prosecution, throughout the United States, concerning fraud in RRB benefit programs. OI conducts investigations relating to the fraudulent receipt of RRB disability, unemployment, sickness, and retirement/survivor benefits. OI investigates railroad employers and unions when there is an indication that they have submitted false reports to the RRB. OI also conducts investigations involving fraudulent claims submitted to the Railroad Medicare Program. These investigative efforts can result in criminal convictions, administrative sanctions, civil penalties, and the recovery of program benefit funds.

OI INVESTIGATIVE RESULTS FOR FISCAL YEAR 2010

Civil Judgments	19
Indictments/Informations	47
Convictions	50
Recoveries/Receivables	\$29,296,188

OI anticipates an ongoing caseload of about 450 investigations in fiscal year 2012. During fiscal year 2010, OI opened 244 new cases and closed 210. To date in fiscal year 2011, OI has opened 188 new cases and closed 135. At present, OI has cases open in 47 States, the District of Columbia, and Canada with estimated fraud losses of over \$37 million. Disability fraud cases represent the largest portion of OI's total caseload. These cases involve more complicated schemes and often result in the recovery of substantial amounts for the RRB's trust funds. They also require considerable resources such as travel by special agents to conduct surveillance, numerous witness interviews, and more sophisticated investigative techniques. Additionally, these fraud investigations are extremely document-intensive and require forensic financial analysis.

During fiscal year 2012, OI will continue to coordinate its efforts with agency program managers to address vulnerabilities in benefit programs that allow fraudulent activity to occur and will recommend changes to ensure program integrity. OI plans to continue proactive projects to identify fraud matters that are not detected through the agency's program policing mechanisms.

CONCLUSION

In fiscal year 2012, the OIG will continue to focus its resources on the review and improvement of RRB operations and will conduct activities to ensure the integrity of the agency's trust funds. This office will continue to work with agency officials to ensure the agency is providing quality service to railroad workers and their families. The OIG will also aggressively pursue all individuals who engage in activities to fraudulently receive RRB funds. The OIG will continue to keep the Subcommittee and other members of Congress informed of any agency operational problems or deficiencies.

The OIG sincerely appreciates its cooperative relationship with the agency and the ongoing assistance extended to its staff during the performance of their audits and investigations. Thank you for your consideration.

NONDEPARTMENTAL WITNESSES

PREPARED STATEMENT OF ADAP ADVOCACY ASSOCIATION

Thank you on behalf of the ADAP Advocacy Association (aaa+) and its board of directors for the opportunity to submit our written testimony to the Senate Committee on Appropriations, Subcommittee on Labor, Health and Human Services and Education (LHHSE) about the AIDS Drug Assistance Programs (ADAPs). aaa+ is a national 501(c)(3) nonprofit organization incorporated in the District of Columbia to promote and enhance the AIDS Drug Assistance Programs and improve access to care for persons living with HIV/AIDS. We appreciate the opportunity to share our testimony on fiscal year 2010 appropriations.

State ADAPs are primarily federally funded under Part B of the Ryan White Comprehensive AIDS Resources Emergency (CARE) Act. ADAPs provide medications to treat HIV disease and prevent and treat AIDS-related opportunistic infections to low income, uninsured and underinsured individuals living with HIV/AIDS in the 50 States, District of Columbia, Puerto Rico, Guam, U.S. Virgin Islands, American Samoa, Marshall, and Northern Marianas Islands. Additional funding is directed toward State ADAPs from other Ryan White CARE Act funds, including Part A Eligible Metropolitan Area (EMA) funds. Many States also directly contribute funding. ADAPs represent the “access to treatment” window for the community-based continuum of HIV/AIDS healthcare so carefully built and supported by all the parts of the Ryan White CARE Act, which was reauthorized for 4 years by both Houses of Congress and signed into law by President Barack Obama on October 30, 2009. The law in general has enjoyed strong bipartisan support since it was first passed in the 1990s, and ADAPs specifically have been a Return on Investment (ROI) model since the Federal Government began pumping money into them when President Bill Clinton and Speaker Newt Gingrich were in office.

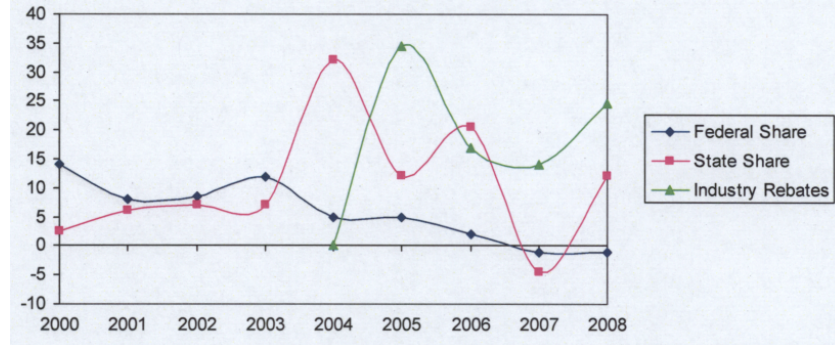
At the time when our testimony is being submitted to the subcommittee for its consideration, there are 7,553 people living with HIV/AIDS in 11 States on ADAP waiting lists—including 31 people in Arkansas, 3,848 people in Florida, 1,221 people in Georgia, 11 people in Idaho, 816 people in Louisiana, 21 people in Montana, 177 people in North Carolina, 303 people in Ohio, 560 people in South Carolina, 563 people in Virginia and 2 people in Wyoming. Overall, 95.54 percent of these people reside in the South. Additionally, it is being submitted for the people living with HIV/AIDS who are the “invisible” waiting lists because they have been kicked-off the program due to changes in eligibility requirements—including 99 people in Arkansas, 257 people in Ohio, and 89 people in Utah, as well as the 6,500+ people in Florida who have been transitioned off the program.

Faced with the “Perfect Storm” that is being fueled by high unemployment, record number of uninsured, State budgetary cutbacks, high cost of medications and inadequate Federal funding, there are a historic number of people being denied access to treatment. Without the subcommittee’s leadership and fortitude to recognize the ROI from ADAPs, several thousand people living with HIV/AIDS will be at risk of developing Opportunistic Infections (OIs), and thousands of others who are HIV-negative will be at greater risk of contracting the virus because their HIV-positive counterparts are more infectious when not taking Highly Active Anti-Retroviral Therapy (HAART).

Each year a sophisticated pharmacoeconomic model is employed by the ADAP Coalition—a unique coalition of AIDS advocates, community-based organizations and representatives of research-based pharmaceutical and biotechnology companies—referencing the data collected from ADAPs from the previous 2 years to forecast the dollar resources that will be needed for the coming 2 years to enable ADAPs to provide HAART (combination antiretroviral therapy) to Americans living with HIV disease.

Many are familiar with this process and its remarkable accuracy over the past 12 years. The Congress and White House have provided us with support very close to the amounts we projected in fiscal year 1996, 1997, 1998, 1999, 2000, always in amounts above the original Administration budget requests; funding in subsequent fiscal year 2001–05 was sustainable, but often short of the necessary amounts needed to avert waiting lists. Between 2000 and 2008, States increased their share of the ADAP budget by 155 percent while the Federal Government increased its share by only 46 percent overall. The chart shows the increase by each party each year

over the previous fiscal year in percentage points. States have basically increased—as well as pharmaceutical rebates—while the Federal commitment has gone down!



The ongoing ADAP crisis is being fueled, by in large, because Federal spending has been inadequate—despite small budget increases under both President George W. Bush and President Obama since 2005. The Federal share of ADAP funding has fallen steadily over the last several years. In fiscal year 2003 the Federal earmark was 72 percent of the overall ADAP budget. In fiscal year 2009, the Federal share had fallen to 49 percent of the ADAP budget. ADAPs have long had a strong State-Federal partnership; however despite the economic downturn many States have increased funding in fiscal year 2010 by an additional \$121 million for a total of \$346.2 million. Pharmaceutical manufacturers have also helped to alleviate fiscal challenges for ADAP by agreeing to lower drug prices and enhance rebates, which amounted to \$259 million in saving for fiscal year 2009. Supplemental agreements will save an additional \$160 million per year starting in July 2010.¹

ADAPs truly need an increase of \$410 million in fiscal year 2012 to maintain their programs and fill the structural deficits that have built up over the last several years. In fiscal year 2012, the HIV/AIDS community is asking for an increase of \$131 million to continue to serve an average of 1,312 new clients per month. The funding level of \$991 million is the authorized level in the Ryan White reauthorization of 2009.²

A large gap remains for ADAPs in fiscal year 2010. Included in the fiscal year 2011 need number was a revised estimate for the ADAP Federal need number for fiscal year 2010 of \$961 million, an increase of \$126 million over the current funding level. The fiscal year 2010 need number was revised based upon new survey data. Coupled with estimated State funding, this funding will provide continued services to a total of 153,875 clients in fiscal year 2010, including the ability to enroll 15,760 new clients and eliminate waiting lists. This includes individuals who are fully covered by ADAP and those who receive assistance with Medicare Part D cost sharing requirements or private insurance continuation. The fiscal year 2010 need number has been adjusted from the previous level to account for the \$20 million already received through the fiscal year 2010 Congressional appropriations process.³ This problem is only worsens moving into fiscal year 2012.

The problem of growing ADAP waiting lists is exacerbated because we are facing an American HIV/AIDS epidemic of devastating proportion. According to some estimates, the number of people living with HIV/AIDS in the United States was approximately 2 million by the end of 2010. These numbers are not due to decrease in the near future. In 2006 alone, the Centers for Disease Control and Prevention (CDC) estimated that there have been more than 56,000 new HIV infections per year for the last decade. If this was not severe enough, the disease is far from color blind. Currently, the incidence rate of new HIV infection among African American men and women is seven times that of the Caucasian population. Furthermore, racial disparities are echoed regionally as the epidemic has seen its most recent unfettered growth in southern States, which often times have smaller State budgets and fewer access points to comprehensive care.

The ADAP need is being driven by simple factors. As we all know HAART AIDS treatments has dropped U.S. death rates from AIDS by about 75 percent starting

¹ The ADAP Coalition, ADAP Need Fiscal Year 2012, January 2011.

² The ADAP Coalition, ADAP Need Fiscal Year 2012, January 2011.

³ The ADAP Coalition, ADAP Need Fiscal Year 2010 & Fiscal Year 2011, January 2010.

in 1996. Whereas annual AIDS deaths used to run about 40,000 a year, now 15,000 to 17,000, even less in areas of very good medical care.

While dramatic improvements in lifespan and quality of life are almost miraculous, HAART treatments must continue for ADAP patients. Therefore patients living longer will likely require ADAP services for medications longer. There are 200,000 to 300,000 Americans who are unaware that they are HIV+. Extensive multi-million dollar efforts for outreach and HIV testing are going on all over the country, and the CDC now urges routine testing for those at risk for HIV. Funded by churches, foundations, Minority Health Initiatives, pharmaceutical companies and AIDS service groups, these efforts are identifying “hard to reach” populations many of whom lack adequate health insurance. These individuals, when identified, must look to ADAP to cover the costs of their drugs. For most, access to Medicaid is limited. State Medicaid programs typically require disease progression to full-blown AIDS to meet the Social Security definition of disabled. U.S. Government treatment guidelines consider progression to full-blown AIDS to be months and years too late for optimum treatments. As we decided in Congress to allow timely early treatment of breast and cervical cancers in women, so too should we allow States the option to provide early treatments for HIV through Medicaid to both men and women.

While we hope that Congress will pass the Early Treatment for HIV Act (ETHA) to allow States the option to provide HIV care and treatments through Medicaid early in the disease process when health benefits are greater and costs are less, for now we are stuck with folks who can’t qualify for Medicaid looking to ADAP for basic coverage. Increases in private sector health insurance costs forces steady streams of HIV+ patients from private health insurance programs to State ADAPs. This is a result of rising costs in premiums and co-payments that become unaffordable, and in some instances by HMO-type providers with drug benefits leaving the market for more profitable locations. These factors together, ensure need for State ADAPs for the coming years. The increasing rate of need will be substantial until key provisions of the Patient Protection and Affordable Care Act (PPACA) can provide adequate benefits to our entire senior, elderly and disabled populations. As the profile of the American AIDS epidemic has expanded further into communities of color, marginalized populations, rural areas, and particularly to women of color in their child bearing years, ADAPs feel these additional strains from groups which traditionally may work low-paying jobs with inadequate health insurance or no healthcare benefits.

In the past 12 months, 20 State ADAPs have instituted other cost-containment strategies. ADAPs with other cost-containment strategies instituted since April 1, 2009, as of February 2, 2011) include: Arizona: Reduced formulary, Arkansas: Reduced formulary, lowered financial eligibility to 200 percent of FPL, (disenrolled 99 clients in September 2009), Colorado: Reduced formulary, Florida: Reduced formulary, lower financial eligibility to 300 percent FPL, transition clients to Welvista from 2/14–3/31/11, Georgia: Reduced formulary, implemented medical criteria, continued participation in the Alternative Method Demonstration Project (AMDP), Idaho: Capped enrollment, Illinois: Reduced formulary, instituted monthly expenditure cap, Kentucky: Reduced formulary, Louisiana: Discontinued reimbursement of laboratory assays, North Carolina: Reduced formulary, North Dakota: Capped enrollment, instituted annual expenditure cap, lowered financial eligibility to 300 percent FPL, Ohio: Reduced formulary, lowered financial eligibility to 300 percent of FPL (disenrolled 257 clients), Puerto Rico: reduced formulary, South Carolina: Lowered financial eligibility to 300 percent FPL, Utah: Reduced formulary, lowered financial eligibility to 250 percent of FPL (disenrolled 89 clients), Virginia: Reduced formulary, only distribute 30-day prescription refills, Washington: Instituted client cost sharing, reduced formulary (for uninsured clients only), only pay insurance premium for clients currently on antiretrovirals, and Wyoming: Reduced formulary, instituted client cost sharing.

As previously stated, ADAP waiting lists—as well as the aforementioned cost-containment strategies put the lives of people living with HIV/AIDS at risk (e.g., developing OIs), as well as put HIV-negative people at higher risk of becoming infected (e.g., HIV-positive people are more infectious when not properly treated with HAART). Without congressional leadership and adequate Federal funding, current circumstances could easily lead to a public health emergency that will only cost the taxpayers much more.

In hindsight, it becomes easy to argue that ADAPs have historically been underfunded. In reality however, it is the emergence of highly active anti-retroviral therapy over the past 7 years and the successes of these treatment options that have made dramatic changes in people’s lives; that have made access to HIV treatment and care such a dramatic national policy concern. We now understand how HIV replicates in the body, beginning its destructive impact on the immune system from the

moment of infection. Where in the recent past we divided people into categories such as asymptomatic and symptomatic in order to make treatment decisions, current treatments dictates that we no longer make these distinctions in our approach to therapy. The latter simply reflects a more advanced state of immune damage.

The standard of care today recommends that patients start on antiretroviral therapy with a combination of drugs earlier in the disease in order to preserve immune function. It also presumes the earliest possible knowledge of HIV status and informed medical care to decide the exact timing of treatment commencement and treatment type selection. Improved immune function has a direct impact on those topics you are most likely interested in today, saving and improving the quality of lives and cost savings to the healthcare system.

By now it is really not necessary to explain the benefits of antiretroviral treatments or even its cost effectiveness. Everyone knows these things. In fact thousands of people are dedicated to seeing that the "AIDS miracles" of the last few years available in the United States are delivered to the rest of the world before societal damage in excess of the plagues of the Middle Ages is inflicted upon whole countries in the Caribbean, Africa, Asia and parts of the former Soviet Union. In sharing the wealth of the medical knowledge and expertise, which the United States have lead in developing we must not, and should not forget the homeland. We must make sure that no American with HIV is forgotten and allowed to fall through the cracks. The time has come to end the wait for people living with HIV/AIDS.

In closing the following two hypothetical examples demonstrate the ROI of the AIDS Drug Assistance Program:

—Charlie is a 29-year old black single father living in Gadsden County Florida. He and his wife found out they were infected with HIV when she died from complications of AIDS related pneumonia the previous year. Charlie is on a waiting list to receive AIDS drugs but between his depression and efforts to care for his children he is unable to access the help he needs to navigate the Patient Assistance Programs. He himself gets sick. He enters an emergency room in Tallahassee, Florida and is subsequently admitted for a 5-day stay. His emergency room visit is near the average for this hospital at \$2,783 (source Florida Health Finder.org.) The hospital stay is near the national average of \$24,000. He receives additional bills from doctors, radiologists and therapists for \$750. You can compare this total to the cost of the AIDS drug he would need for an entire year. Charlie is what is known as therapy naive so the most inexpensive combination therapy drugs would be effective in reducing the virus to undetectable levels. The annual drug cost would be around \$15,000 per year. Compare that to \$33,830 in 6 days for hospitalization.

—Now consider Patricia. She has had AIDS for 20 years and the AIDS virus she carries is resistant to all but the most expensive AIDS drugs. She has fallen out of care and is now getting progressively sicker. She goes to ADAP at the nearest county health department which is 20 miles away only to be told that she has been wait listed due to budget shortfalls. Patricia falls ill while trying to navigate assistance programs and is hospitalized. Her ER costs are similar to that of Charlie's but she stays in the hospital for 20 days and then dies. Her costs are well over \$100,000 not including funeral and burial costs. Her drugs would have cost \$30,000 per year.

We urge to you fully fund the ADAP program in fiscal year 2012 with an increase of \$131 million. No one need be denied the new standard of care for HIV disease. We have come too far as a Nation to turn our backs on HIV/AIDS now. Please make sure that the resources are there for every HIV-positive American to be treated regardless of their financial resources or ability to access adequate health insurance coverage.

PREPARED STATEMENT OF THE AD HOC GROUP FOR MEDICAL RESEARCH

The Ad Hoc Group for Medical Research is a coalition of more than 300 patient and voluntary health groups, medical and scientific societies, academic and research organizations, and industry. The Ad Hoc Group appreciates the opportunity to submit this statement in support of enhancing the Federal investment in biomedical, behavioral, and population-based research supported by the National Institutes of Health (NIH).

We are deeply grateful to the Subcommittee for its long-standing, bipartisan leadership in support of NIH. These are difficult times for our Nation and for people all around the globe, but the affirmation of science is the key to a better future. To improve Americans' health and strengthen America's innovation economy, the Ad

Hoc Group for Medical Research recommends \$35 billion for NIH in fiscal year 2012.

The partnership between NIH and America's scientists, medical schools, teaching hospitals, universities, and research institutions continues to serve as the driving force in this Nation's search for ever-greater understanding of the mechanisms of human health and disease. More than 83 percent of NIH research funding is awarded to more than 3,000 research institutions located in every State. These are funded through almost 50,000 competitive, peer-reviewed grants and contracts to more than 350,000 researchers.

The foundation of scientific knowledge built through NIH-funded research drives medical innovation that improves health and quality of life through new and better diagnostics, improved prevention strategies, and more effective treatments. NIH research has contributed to dramatically increased and improved life expectancy over the past century. A baby born today can look forward to an average life span of nearly 78 years—almost three decades longer than a baby born in 1900, and life expectancy continues to increase. People are staying active longer, too: the proportion of older people with chronic disabilities dropped by nearly a third between 1982 and 2005. Thanks to insights from NIH-funded studies, the death rate for coronary heart disease is more than 60 percent lower—and the death rate for stroke, 70 percent lower—than in the World War II era.

NIH research continues to create dramatic new research opportunities, offering hope to the millions of patients awaiting the possibility of a healthier tomorrow. For example, a new ability to comprehend the genetic mechanisms responsible for disease already is providing insights into diagnostics and identifying a new array of drug targets. We are entering an era of personalized medicine, where prevention, diagnosis, and treatment of disease can be individualized, instead of using the standardized approach that all too often wastes healthcare resources and potentially subjects patients to unnecessary and ineffective medical treatments and diagnostic procedures.

Peer-reviewed, investigator-initiated basic research is the heart of NIH research. These inquiries into the fundamental cellular, molecular, and genetic events of life are essential if we are to make real progress toward understanding and conquering disease. The application of the results of basic research to the detection, diagnosis, treatment, and prevention of disease is the ultimate goal of medical research. Clinical research not only is the pathway for applying basic research findings, but it also often provides important insights and leads to further basic research opportunities. Additional funding is needed to sustain and enhance basic and clinical research activities, including increasing support for current researchers and promoting opportunities for new investigators and in those areas of science that historically have been underfunded.

Ongoing efforts to reinvigorate research training, including developing expanded medical research opportunities for minority and disadvantaged students, continue to gain importance. For example, the volume of data being generated by genomics research, as well as the increasing power and sophistication of computing assets on the researcher's lab bench, have created an urgent need, both in academic and industrial settings, for talented individuals well-trained in biology, computational technologies, bioinformatics, and mathematics to realize the promise offered by modern interdisciplinary research.

To move forward, it will be essential to maintain the talent base and infrastructure that has been created to date. Large fluctuations in funding will be disruptive to training, to careers, long range projects and ultimately to progress. The research engine needs a predictable, sustained investment in science to maximize our return.

Further, NIH-supported research contributes to the Nation's economic strength by catalyzing private sector growth and creating skilled, high-paying jobs; new products and industries; and improved technologies. Industries and sectors that benefit include the high-technology and high value-added pharmaceutical and biotechnology industries, among others. In particular, the NIH funds "enabling science" that explores and identifies discoveries at a point earlier than businesses often invest, stoking and sustaining the discovery pipeline.

The investment in NIH not only is an essential element in restoring and sustaining both national and local economic growth and vitality, but also is essential to maintaining this Nation's prominence as the world leader in medical research. As Raymond Orbach, former Under Secretary for Science at the Department of Energy for President George W. Bush, noted in a recent editorial in *Science*, "Other countries, such as China and India, are increasing their funding of scientific research because they understand its critical role in spurring technological advances and other innovations. If the United States is to compete in the global economy, it too must continue to invest in research programs." To succeed in the information-

based, innovation driven world-wide economy of the 21st century, we must recommit to long-term sustained growth in medical research funding.

The ravages of disease are many, and the opportunities for progress across all fields of medical science to address these needs are profound. In this challenging budget environment, we recognize the painful decisions Congress must make. The community appreciates that this subcommittee always has recognized that discoveries gained through basic research yield the medical advances that improve the fiscal and physical health of the country. Strengthening the Nation's commitment to medical research is the key to ensuring the future of America's medical research enterprise and the health of her citizens.

The Ad Hoc Group for Medical Research respectfully requests that NIH be recognized as an urgent national priority as the subcommittee prepares the fiscal year 2012 appropriations bills.

PREPARED STATEMENT OF THE AIDS HEALTHCARE FOUNDATION

On behalf of the over 1 million Americans with HIV/AIDS, and the over 56,000 Americans who will become infected with HIV this year, AIDS Healthcare Foundation (AHF) submits the following recommendations and proposals for funding domestic HIV/AIDS programs for fiscal year 2012.

AHF is the largest HIV/AIDS nonprofit in the United States. For over 20 years, it has delivered high quality medical care, pharmacy services, research, and HIV prevention and testing services throughout the country. It currently provides medical care to over 150,000 people with HIV/AIDS in 22 countries around the world.

Based on this experience, it is clear to AHF that the battle against HIV/AIDS is winnable, and that the keys to winning this fight are:

Find those Americans who have HIV, but don't know it.

It is estimated that approximately 20 percent of all Americans who have HIV do not know they are infected. It is not surprising that this group unwittingly is the source of up to 70 percent of all HIV infections in the United States—if you don't know you have HIV, you don't take steps to protect others, and you don't get treatment.

Provide AIDS drug treatment to all Americans with HIV/AIDS who need it.

It cannot be stressed enough—treatment is prevention. AIDS treatment is one of the most effective tools we have to prevent new infections. The point of treatment is to reduce the amount of the HIV virus in a person. People with HIV/AIDS who are on treatment are less infectious, and simply are far less able to transmit the virus. AIDS treatment is 92 percent effective in preventing new infections.

If we could find those who don't know they have HIV, and get them treatment, new HIV infections would plummet. Not only would these people be healthier and able to work and care for their families, but we would save tens of billions per year in future medical costs.

Currently, there are approximately 56,000 new HIV infections in the United States every year. As the lifetime medical cost (the majority of which will be borne by the Federal Government via Medicare, Medicaid, or the Ryan White CARE Act) for each HIV infection is over \$600,000, the United States accrues over \$36 billion in future medical costs every year due to new HIV infections.

Therefore, effectively battling the AIDS epidemic requires prioritizing scarce funds into two main areas: Testing (to find those who are unaware they have HIV) and treating (providing AIDS drugs and medical care to the newly diagnosed, to prevent new infections).

AHF recognizes the prevailing economic and budget climate, and understands that finding new money to pay for these necessary programs is extremely challenging. AHF therefore makes the following recommendations that would free up existing funding to focus more on testing and treatment:

Re-prioritize AIDS prevention funding within the Centers for Disease Control toward HIV testing.

Yearly new HIV infections have not declined for well over a decade. As a result, it is time to re-think the CDC's approach to HIV prevention. In recent times CDC has spent approximately 30 percent of its HIV prevention budget on HIV testing. AHF recommends that, for fiscal year 2012 and beyond, the CDC be required to spend at least 50 percent of its prevention budget on testing. The more tests the CDC performs, the more people who are unaware of their HIV status will be found, which is the first step in preventing new infections.

Increase funding for the AIDS Drug Assistance Program (ADAP) by \$108 million.

ADAP is a lifeline for thousands of Americans who cannot afford AIDS treatment, which can cost well in excess of \$12,000 per year. Nationwide, ADAP serves over

165,000 people, approximately one-third of all people on AIDS treatment in the United States.

Ensuring access to treatment is the backbone in our fight against HIV/AIDS. Without treatment, people with AIDS become sicker. Without treatment, new infections will increase, and every new infection carries with over \$600,000 in lifetime medical costs. For these reasons, it is of grave concern that access to care for thousands of Americans is now at risk.

Currently, there are over 7,800 Americans on ADAP waiting lists across the country—7,800 people who cannot get access to these drugs due to budgetary constraints. This list continues to grow as infections continue, State financial support is reduced, and drug prices increase.

To reverse this trend, AHF supports the consensus of the AIDS community that ADAP funding should be increased by \$108 million for a total of \$991 million. In the absence of new money, AHF proposes funding this increase via the following means:

Implement administrative and overhead caps within CDC, HRSA, and NIH AIDS programs, and redirect the savings to ADAP.

In tight budgetary times, Government must become more cost effective. Currently, Government agencies like HRSA require that contractors spend no more than 10 percent of grants on administrative overhead. These agencies, which are tasked with implementing ADAP and other AIDS programs, spend a combined \$2.3 billion on administration and overhead. As a recipient of Government funds that has operated under these requirements, AHF submits that these caps should be applied to these agencies as well. Controlling administrative costs will free up money that can be spent on services, not bureaucracy.

Secure additional drug price discounts/rebates from AIDS drug manufacturers.

Drug price increases are one of the main causes of the current ADAP crisis. Additional discounts would mean ADAPs could serve everyone who needs it without new funding. Moreover, given the unique nature of ADAP, these discounts would not have any significant impact on drug company profitability, as they would not impact price calculations for other drug programs or reduce drug company revenues.

AIDS Healthcare Foundation (AHF) supports increasing Federal funding for ADAP. However, additional funding must go hand in hand with changes to ADAP that protect the program from high drug prices. To achieve this, AHF proposes that for every dollar of additional Federal funding drug companies contribute \$2 in additional rebates or price cuts. This would effectively triple the purchasing power of each additional ADAP dollar, and ensure the sustainability of this vital program. Congress can implement this solution by directing the Secretary of Health and Human Services to negotiate the drug company contribution as a condition of receiving new money for ADAP.

Call for the National Institutes of Health to make an independent review of prevention interventions being supported by CDC to determine their effectiveness.

Even though the AIDS epidemic is over 25 years old, there is still very little evidence concerning what prevention programs work, and are cost effective. In order to better target scarce resources to the most effective interventions, AHF recommends that \$1 million of NIH's fiscal year 2012 AIDS research budget be spent on determining which HIV prevention methods are in fact cost-effective ways of reducing HIV infections.

The implementation of the recommendations would forcefully re-orient America's AIDS response in a way that would significantly reduce new infections, save billions of dollars, and improve the health of hundreds of thousands of Americans.

PREPARED STATEMENT OF AIDS UNITED

On behalf of AIDS United and our diverse partner organizations I am pleased to submit this testimony to the Members of this Subcommittee on the urgency of needed funding for the fiscal year 2012 domestic HIV/AIDS portfolio. AIDS United is a national organization that seeks to end the AIDS epidemic in the United States by combining private-sector fundraising, philanthropy, coalition building, public policy expertise, and advocacy—as well as a network of passionate local and State partners—to effectively and efficiently respond to the HIV/AIDS epidemic in the communities most impacted by it. Through its unique Community Partnerships program, Public Policy Committee and targeted special grant-making initiatives, AIDS United represents over 400 grassroots organizations. These organizations provide HIV prevention, care, treatment, and support services to underserved individuals and populations most impacted by the HIV/AIDS epidemic including communities of color,

women and people living with HIV/AIDS in the United States as well as education and training to providers of treatment services.

June 5, 2011 marks the 30th year since the Centers for Disease Control and Prevention (CDC) reported the first cases of what later became identified as HIV disease. Sadly, the HIV/AIDS epidemic in the United States is characterized by need-less mortality, inadequate access to care, persistent levels of new infection, and stark population and regional disparities. Although improved treatment has made it possible for people with HIV disease to lead longer and healthier lives, these stark realities remain.

HIV Remains a Major Public Health Danger

More than 1.2 people are living with HIV or AIDS; nearly one-half living with HIV/AIDS are not in care.

56,300 people are estimated to have been newly infected with HIV in the United States in 2006, the year for which the most recent data is available—one new infection every 9½ minutes. According to the Centers for Disease Control and Prevention (CDC) the HIV infection rate has not fallen in 16 years.

There is neither a cure nor a vaccine for HIV and current treatments do not work for everyone.

HIV Severely Affects African Americans, Latinos, Women and Gay Men

African Americans represent 13 percent of the United States population but nearly 50 percent of all newly reported HIV infections.

Hispanics/Latinos represent 13 percent of the United States population but account for 18 percent of newly reported cases of HIV.

The percentage of newly reported HIV/AIDS cases in the United States among women tripled from 8 percent to 27 percent between 1985 and 2007. AIDS is a leading cause of death among black women aged 15–54.

Gay, bisexual, and other men who have sex with men, especially in communities of color, are the population most severely affected by HIV.

AIDS United Supports the Goals of the National HIV/AIDS Strategy

The Federal Government has created a first ever National HIV/AIDS Strategy that commits to four basic goals: reducing the number of people who become infected with HIV; increasing access to care and optimizing health outcomes for people living with HIV; reducing HIV-related health disparities; and achieving a more coordinated national response to the HIV Epidemic.

AIDS United strongly supports achievement of these goals and strongly urges the Labor, Health and Human Services, and Education Subcommittee of the Senate Appropriations Committee to ensure that meeting these goals is a top priority. Unfortunately given the growth in the epidemic, meeting these goals, particularly lowering the new HIV infection rate, will require greater funding than has been made available. The Federal Government's commitment to HIV domestic funding is even more important this year as we see many States lowering their State funding contributions due to the economic realities States are facing. AIDS United strongly urges Congress to meet this challenge through the good work of this subcommittee and to recognize and address the true funding needs of the programs in the HIV/AIDS portfolio.

AIDS Budget and Appropriations Coalition HIV Community Fiscal Year 2012 Request (Increases Over Fiscal Year 2010)

The HIV community has come together under the umbrella of the AIDS Budget and Appropriations Coalition with the community funding request for the HIV/AIDS domestic portfolio for fiscal year 2012, the comparisons are based on fiscal year 2010 finals. We fully understand the budgetary constraints that are impacting this time, but we feel it is imperative to let this subcommittee know of the true needs in the HIV community.

HIV Prevention.—According to CDC estimates contained in the agency's 2009 HIV/AIDS Surveillance Report, since the beginning of the epidemic there have been 1,142,714 AIDS cases reported with a total of 617,025 deaths in the United States. Based on previous CDC estimates more than 1.2 million people are living with HIV/AIDS and that an estimated 21 percent of people living with HIV are unaware of their HIV status and could unknowingly transmit the virus to another person. Prior to fiscal year 2010 funding had remained flat for more than 8 years. As a result, grants to States and local communities have decreased significantly even as the United States seeks to increase prevention and testing services. To begin to reach the goals of the National HIV/AIDS Strategy the Congress must give the CDC the necessary funding to invest in meaningful prevention. AIDS United requests an in-

crease of at least \$57.2 million to \$857.6 million in fiscal year 2012 to address the true need of \$1,324.6 billion.

Education.—The National HIV/AIDS Strategy acknowledges the need to educate all Americans about the threat of HIV and how to prevent it. The United States must invest in programs that provide our young people with complete, accurate, and age-appropriate sex education that helps them reduce their risk of HIV, other STDs, and unintended pregnancy. AIDS United supports the Administration's teen pregnancy prevention initiative but urges Congress to find opportunities to fund true, comprehensive sex education that promotes healthy behaviors and relationships for all young people, including LGBT youth. Negative health outcomes are related to lack of knowledge and we must provide youth with the information and services they need to make responsible decisions about their sexual health. AIDS United requests that the teen pregnancy prevention initiative funding increase by \$6.7 million to a level of \$161.4 million. AIDS United also requests an increase of \$10 million, for a total of \$50 million, for the Division of Adolescent and School Health's HIV Prevention Education at the CDC. AIDS United is pleased that the President's budget includes zero funding for failed abstinence-only-until-marriage programs and urges the subcommittee also to ensure that funding is not included for these ineffective programs.

Policy Rider, Syringe Exchange.—CDC estimates that approximately 13 percent of all HIV cases and 60 percent of all hepatitis C cases in the United States are related to intravenous drug use. Eight Federal studies and numerous scientific peer reviewed papers have conclusively established that syringe exchange programs reduce the incidence of HIV among people who inject drugs and their sexual partners and that syringe exchange reduces drug abuse. Syringe exchange programs connect people who use drugs to healthcare services including substance abuse treatment, HIV and viral hepatitis prevention services and testing, counseling, education, and support. AIDS United recommends that the Subcommittee maintain the current compromise language letting local jurisdictions make their own decision about using Federal funds to prevent HIV and viral hepatitis through the use of proven syringe exchange programs.

HIV/AIDS Treatment.—The Ryan White HIV/AIDS Treatment Extension Act, administered by the Health Resources and Services Administration (HRSA) provides services to more than 529,000 people living with and affected by HIV throughout the United States and its territories. It is the largest source of Federal funding solely focused on the delivery of HIV services and has provided the framework for our national response to the HIV epidemic. In recent years, funding for the Ryan White Program has not kept pace with the growing epidemic leading to waiting lists and other cost containment measures for the AIDS Drug Assistance Program (ADAP), increasing wait times to receive medical appointments and loss of some support services. Ryan White Programs are designed to compliment each other. As such, all parts of the Ryan White Program require substantial increased funding to address the true needs of the hundreds of thousands of people living with HIV who are uninsured, underinsured, or who lack financial resources for healthcare and require Ryan White Program services. AIDS United recommends that the Ryan White Program funding level be increased by \$369.7 million to a total of \$2.686 billion in fiscal year 2012.

Ryan White Programs, Part A.—This Part of the Ryan White Programs provides physician visits, laboratory services, case management, home-based and hospice care, and substance abuse and mental health services in the jurisdictions most affected by HIV/AIDS. These core medical and supportive services are critical to ensuring patients have access to and can effectively utilize life-saving therapies. AIDS United recommends funding for Part A at \$751.9 million, an increase of \$73.8 million in fiscal year 2012.

Ryan White Programs, Part B (base).—This program ensures a foundation for HIV related healthcare services in each State and territory, including the critically important ADAP. Part B base grants (excluding ADAP). AIDS United recommends funding for Part B base grants at \$495.0 million, an increase of \$76.2 million in fiscal year 2012.

Ryan White Programs, Part B (ADAP).—The AIDS Drug Assistance Program provides medications for treating people with HIV who cannot access Medicaid or private health insurance. According to the 2011 National ADAP Monitoring Project, ADAP provided drugs to about 190,936 clients in fiscal year 2009, including 33,672 new clients. As of April 15, 2011, 11 State ADAPs had waiting lists of 7,885 individuals and an additional 8 States had taken or were considering taking cost-containment measures. According to a respected pharmacoeconomic study that measures the funds needed to let State ADAPs provide a minimum clinical standard formulary the actual need for increases last year was more than \$370.1 million. The

community recognizes the difficult budget environment and asks for a much lower amount. AIDS United recommends \$991 million, the authorized amount for ADAP, an increase of \$131 million, in fiscal year 2012.

Ryan White Programs, Part C.—This Part awards grants to community-based clinics and medical centers, hospitals, public health departments, and universities in 22 States and the District of Columbia under the Early Intervention Services program. These grants are targeted toward new and emerging sub-populations impacted by the HIV epidemic. Part C funds are particularly needed in rural areas where the availability of HIV care and treatment is still relatively new. AIDS United requests \$272.2 million, the authorized amount for Part C an increase of \$65.8 million, in fiscal year 2012.

Ryan White Programs, Part D.—Part D awards grants under the Comprehensive Family Services Program to provide comprehensive care for HIV positive women, infants, children, and youth and their affected families. These grants fund the planning of services that provide comprehensive HIV care and treatment and the strengthening of the safety net for HIV positive individuals and their families. AIDS United requests \$83.1 million, an increase of \$5.5 million, for Part D.

Ryan White Programs, Part F, the AIDS Education and Training Centers (AETCs).—The AETCs train Ryan White program doctors, advanced practice nurses, physicians' assistants, nurses, oral health professionals, and pharmacists about HIV treatment, testing, viral hepatitis and more. The AETCs also ensure that education is available to primary healthcare providers who do not specialize in HIV but are asked to treat the increasing numbers of HIV positive patients who depend on them for care. AIDS United requests a total of \$50 million, a \$15.2 million increase in fiscal year 2012.

Ryan White Programs, Part F, Dental Care.—Dental care is a crucial service needed by people living with HIV disease. Oral health problems are often an early manifestation of HIV disease. Unfortunately oral health is often neglected by those who cannot afford, or do not have access to, proper medical care creating missed opportunities to find early HIV infections. AIDS United request \$19 million, a \$5.4 million increase, for this program in fiscal year 2012.

Department of Health and Human Services, Minority AIDS Initiative.—The Minority AIDS Initiative directly benefits racial and ethnic minority communities that are the most deeply affected by HIV/AIDS infection rates with grants to provide technical assistance, infrastructure support and strengthen the capacity of minority community based organizations to deliver high-quality HIV healthcare and supportive services. Communities of color are deeply affected by the HIV epidemic. The Minority AIDS Initiative funds needed programs throughout HHS agencies and is included in every Part of the CARE Act. It was authorized within the Ryan White Program for the first time in 2006. AIDS United requests a total of \$610 million for the Minority AIDS Initiative.

HIV/AIDS Research.—Research to prevent, treat and ultimately cure HIV is vital to the domestic and global control of the disease. The United States through the National Institute of Health (NIH) must continue to take the lead in the research and development of new medicines to treat current and future strains of HIV. The NIH's Office of AIDS Research must continue its groundbreaking research in both basic and clinical science to develop a preventative vaccine, microbicides, and other scientific, behavioral, and structural HIV prevention interventions. Commitment to research will ultimately help to bring the epidemic under control decreasing the funds that must be spent on care and treatment of HIV. AIDS United requests that the NIH be funded at \$35 billion in fiscal year 2012 and the AIDS portfolio be funded at \$3.5 billion, a \$410 million increase.

The HIV epidemic is a continuing health crisis in the United States. We must expand resources for our domestic HIV prevention, treatment and care, and research efforts to meet the goals of the National HIV/AIDS Strategy. On behalf of our more than 400 participating organizations, HIV positive Americans and those affected by this disease, AIDS United urges the subcommittee help us save lives by to fully funding the domestic response to the ongoing, tragic, HIV epidemic in the United States.

PREPARED STATEMENT OF THE ADULT CONGENITAL HEART ASSOCIATION

Introduction

The Adult Congenital Heart Association (ACHA)—a national non-for-profit organization dedicated to improving the quality of life and extending the lives of adults with congenital heart disease (CHD)—is grateful for the opportunity to submit written testimony regarding fiscal year 2012 funding for congenital heart research and

surveillance. We respectfully request \$3 million for CHD surveillance at the Centers for Disease Control and Prevention (CDC) as well as additional CHD research at the National Heart, Lung and Blood Institute (NHLBI).

Adult Congenital Heart Disease

Congenital heart defects are the most common group of birth defects occurring in approximately 1 percent of all live births, or 40,000 babies a year. These malformations of the heart and structures connected to the heart either obstruct blood flow or cause it to flow in an abnormal pattern. This abnormal heart function can be fatal if left untreated. In fact, congenital heart defects remain the leading cause of birth defect related infant deaths.

Many infants born with congenital heart problems require intervention in order to survive. Intervention often includes one or multiple open-heart surgeries; however, surgery is rarely a long-term cure. The success of childhood cardiac intervention has created a new chronic disease—CHD. Thanks to the increase in survival, of the nearly 2 million people alive today with CHD, more than half are adults, increasing at an estimated rate of 5 percent each year. Few congenital heart survivors are aware of their high risk of additional problems as they age, facing high rates of neuro-cognitive deficits, heart failure, rhythm disorders, stroke, and sudden cardiac death, and many survivors require multiple operations throughout their lifetime. 50 percent of all congenital heart survivors have complex problems for which life-long care from congenital heart specialists is recommended, yet less than 10 percent of adult congenital heart patients receive recommended cardiac care. Delays in care can result in premature death and disability. In adults, this often occurs during prime wage-earning years.

ACHA

ACHA serves and supports the more than 1 million adults with CHD, their families and the medical community—working with them to address the unmet needs of the long-term survivors of congenital heart defects through education, outreach, advocacy, and promotion of ACHD research.

In order to promote life-saving research and accessible, appropriate and quality interventions which, in turn, will reduce the public health burden of this chronic disease, ACHA advocates for adequate funding of CDC initiatives relating to CHD, and encourages funding within the National Institutes of Health (NIH) for CHD research. ACHA continues to work with Federal and State policy makers to advance policies that will improve and prolong the lives of those living with CHD.

ACHA is also a founding member of the Congenital Heart Public Health Consortium (CHPHC). The CHPHC is a group of organizations uniting resources and efforts to prevent the occurrence of CHD and enhance and prolong the lives of those with CHD through targeted public health interventions by enhancing and supporting the work of the member organizations. Representatives of Federal agencies serve in an advisory capacity. In addition to ACHA, the Alliance for Adult Research in Congenital Cardiology, American Academy of Pediatrics, American College of Cardiology, American Heart Association, March of Dimes Foundation, National Birth Defects Prevention Network, and the National Congenital Heart Coalition are all members of the CHPHC.

Federal Support for Congenital Heart Disease Research and Surveillance

Despite the prevalence and seriousness of the disease, CHD data collection and research are limited and almost non-existent for the adult CHD population. In 2004, the NHLBI convened a working group on CHD, which recommended developing a research network to conduct clinical research and establishing a national database of patients.

In March 2010, the first CHD legislation passed as part of Patient Protection and Affordable Care Act (ACA).¹ The ACA calls for the creation of The National Congenital Heart Disease Surveillance System, which will collect and analyze nationally representative, population-based epidemiological and longitudinal data on infants, children, and adults with CHD to improve understanding of CHD incidence, prevalence, and disease burden and assess the public health impact of CHD. It also authorized the NHLBI to conduct or support research on CHD diagnosis, treatment, prevention and long-term outcomes to address the needs of affected infants, children, teens, adults, and elderly individuals. These provisions included in the ACA were originally in the Congenital Heart Futures Act (H.R. 1570/S.621, 111th Congress), which garnered bi-partisan support in both the House and Senate and was

¹ Patient Protection and Affordable Care Act, § 10411(b).

championed by Senators Richard Durbin (D-IL) and Thad Cochran (R-MS), Representative Gus Bilirakis (R-FL) and former Representative Zack Space (D-OH).

Recently, the National Center on Birth Defects and Developmental Disabilities included preventing congenital heart defects and other major birth defects, in its recently published 2011–2015 Strategic Plan, specifically recognizing the need for understanding the contribution of birth defects to longer term outcomes (i.e., beyond infancy) and the economic impact of specific birth defects.

The National Congenital Heart Disease Surveillance System at CDC

As survival improves, so does the need for population-based surveillance across the lifespan. Funding to support the development of the National Congenital Heart Disease Surveillance System through both a pilot adult surveillance program, and the enhancement of the existing birth defects surveillance system will be instrumental in driving research, improving interventional outcomes, improving loss to care, and assessing healthcare burden. In turn, the National Congenital Heart Disease Surveillance System can serve as a model for all chronic disease states.

The current surveillance system is grossly inadequate. There are only 14 States currently funded by the CDC to gather data on birth defects, presenting limitations in generalizing the information across the entire population. Thus, there are significant inconsistencies in the methods of collection and reporting across the various State systems which limits the value of the data. Given the absence of population-based data across the lifespan, the data we do have excludes anyone diagnosed after the age of one, as well as those who are lost to care. It is this population, those lost to care, that is of greatest concern, and most difficult to identify. Evidence indicates that those with CHD are at significant risk for heart failure, rhythm disorders, stroke, and sudden cardiac death as they age, requiring ongoing specialized medical care. For those who are lost to care, for reasons such as limited access to affordable or appropriate care or poor education about the need for ongoing care, they often return to the system with preventable advanced illness and/or disability. Population based surveillance across the life span is the only method by which these patients can be identified, and, as a result, appropriate intervention can be planned. ACHA is currently working with the CDC to address these concerns through the National Congenital Heart Disease Surveillance System.

ACHA requests that Congress provide the CDC \$3 million in fiscal year 2012 to support data collection to better understand CHD prevalence and assess the public health impact of CHD. This level of funding will support a pilot adult surveillance system and allow for the enhancement of the existing birth defects surveillance system.

Funding of Research Related to Congenital Heart Disease at NIH

Our Nation continues to benefit from the single largest funding source for CHD research, the NIH. Yet, as a leading chronic disease, congenital heart research is significantly underfunded.

The NHLBI supports basic and clinical research to establish a scientific basis for the prevention, detection, and treatment of congenital heart disease. The Bench to Bassinet Program is a major effort launched by the NHLBI to hasten the pace at which heart research on genetics and basic science can be developed into new treatments across the life span for people with congenital heart disease. The overall goal is to provide the structure to turn knowledge into clinical practice, and use clinical practice to inform basic research.

ACHA urges Congress to support the NHLBI in efforts to continue its work with patient advocacy organizations, other NIH Institutes, and the CDC to expand collaborative research initiatives and other related activities targeted to the diverse life-long needs of individuals living with congenital heart disease.

Summary

Thank you for the opportunity to highlight this important disease. We know that you face many difficult funding decisions for fiscal year 2012 and hope that you consider addressing the life-long needs of those with CHD. By making an investment in the research and surveillance of CHD, the return will be seen through reduced healthcare costs, decreased disability and improved productivity in a population quickly approaching 2 million.

PREPARED STATEMENT OF THE ALLIANCE FOR AGING RESEARCH

Chairman Harkin and members of the Subcommittee, for 25 years the not-for-profit Alliance for Aging Research has advocated for medical research to improve the quality of life and health for all Americans as we grow older. Our efforts have

included supporting Federal funding of aging research by the National Institutes of Health (NIH), through the National Institute on Aging (NIA) and other NIH institutes and centers. The Alliance appreciates the opportunity to submit testimony highlighting the important role that the NIH plays in facilitating aging-related medical research activities and the ever more urgent need for increased Federal investment and focus to advance scientific discoveries to keep individuals healthier longer.

Research toward healthier aging has never been more critical for so many Americans. In January 2011, the first of the baby boomers began turning age 65. Older Americans now make up the fastest growing segment of the population. According to the U.S. Census Bureau, the number of people age 65 and older will more than double between 2010 and 2050 to 88.5 million or 20 percent of the population; and those 85 and older will increase three-fold, to 19 million, according to the U.S. Census Bureau. Late-in-life diseases such as type 2 diabetes, cancer, neurological diseases, heart disease, and osteoporosis are increasingly driving the need for healthcare services in this country. Many diseases of these aging are expected to become more prevalent as the number of older Americans increases. Preventing, treating or curing chronic diseases of the aging, is perhaps the single most effective strategy in reducing national spending on healthcare.

Consider that the number of Americans age 65 and older with Alzheimer's disease is projected to more than double by 2030. A report in the *Journal of Clinical Oncology* projected cancer incidence will increase by about 45 percent from 2010–2030, accounted for largely by cancer diagnoses in older Americans and minorities, and by 2030, people aged 65 and older will represent 70 percent of all cancer diagnoses in the United States. Currently, the average 75-year old has three chronic health conditions and takes five prescription medications. Six diseases—heart disease, stroke, cancer, diabetes, Alzheimer's and Parkinson's diseases—cost the United States over \$1 trillion each year. In the absence of new discoveries to better treat and prevent osteoporosis, it is estimated to cost the United States \$25.3 billion per year by 2025. According to an Alzheimer's Association report from 2010, research breakthroughs that slow the onset and progression of Alzheimer's disease could yield annual Medicare savings of \$33 billion in 2020 and as much as \$283 billion by 2050.

The rising tide of chronic diseases of aging threatens to overwhelm the U.S. healthcare system in the coming years. Research which leads to a better understanding of the aging process and human vulnerability to age-related diseases could be the key to helping Americans live longer, more productive lives, and simultaneously reduce the need for care to manage costly chronic diseases. Scientists who study aging now generally agree that aging is malleable and capable of being slowed. Rapid progress in recent years toward understanding and making use of this malleability has paved the way for breakthroughs that could increase human health in later life by opposing the primary risk factor for virtually every disease we face as we grow older—aging itself. Better understating of this “common denominator” of disease could usher in a new era of preventive medicine, enabling interventions that stave off everything from dementia to cancer to osteoporosis. As we now confront unprecedented aging of our population and staggering increases in chronic age-related diseases and disabilities, a modest extensions of healthy lifespan could produce outsized returns of extended productivity, reduced caregiver burdens, lessened Medicare spending, and more effective healthcare in future years.

The NIA leads national research efforts within the NIH to better understand the aging process and ways to better maintain the health and independence of Americans as they age. NIA is poised to accelerate the scientific discoveries. The science of aging is showing increasing power to address the leading public health challenges of our time. Leaders in the biology of aging believe it is now realistically possible to develop interventions that slow the aging process and greatly reduce the risk of many diseases and disabilities, including cancer, diabetes, Alzheimer's disease, vision loss and bone and joint disorders. While there has been great progress in aging research, a large gap remains between promising basic research and healthcare applications. Closing that gap will require considerable focus and investment. Key aging processes have been identified by leading scientists as potentially yielding crucial answers in the next 3–10 years. These include stress response at the cellular level, cell turnover and repair mechanisms, and inflammation.

A central theme in modern aging research—perhaps its key insight—is that the mutations, diets, and drugs that extend lifespan in laboratory animals by slowing aging often increase the resistance of cells, and animals, to toxic agents and other forms of stress. These discoveries have two main implications, each of which is likely to lead to major advances in anti-aging science in the near future.

First is the suggestion that stress resistance may itself be the facilitator (rather than merely the companion) of the exceptional lifespan in these animal models,

hinting that studies of agents that modulate resistance to stress could be a potent source of valuable clinical leverage and preventive medicines. Second is the observation that the mutations that slow aging augment resistance to multiple varieties of stress—not just oxidation, or radiation damage, or heavy metal toxins, but rather resistance to all of these at the same time.

The implication is that cells have “master switches,” which, like rheostats that can brighten or dim all lights in a room, can tweak a wide range of protective intracellular circuits to tune the rate of aging differently in long-lived versus short-lived individuals and species. If this is correct, research aimed at identifying these master switches, and fine-tuning them in ways that slow aging without unwanted side-effects, could be the most effective way to postpone all of the physiological disorders of aging through manipulation of the aging rate itself. Researchers have formulated, and are beginning to pursue, new strategies to test these concepts by analysis of invertebrates, cells lines, laboratory animals and humans, and by comparing animals of species that age more quickly or slowly.

One hallmark of aging tissues is their reduced ability to regenerate and repair. Many tissues are replenished by stem cells. In some aged tissues, stem cell numbers drop. In others, the number of stem cells changes very little—but they malfunction. Little is currently known about these stem cell declines, but one suspected cause is the accumulation of “senescent” cells. Cellular senescence stops damaged or distressed cells from dividing, which protects against cancer. At advanced ages, however, the accumulation of senescent cells may limit regeneration and repair, a phenomenon that has raised many questions. Do senescent cells, for instance, alter tissue “microenvironments,” such that the tissue loses its regenerative powers or paradoxically fuel the lethal proliferation of cancer cells?

A robust research initiative on these issues promises to illuminate the roots of a broad range of diseases and disabling conditions, such as osteoporosis, the loss of lean muscle mass with age, and the age-related degeneration of joints and spinal discs. The research is also essential for the development of stem cell therapies, the promise of which has generated much public excitement in recent years. This is because implanting stem cells to renew damaged tissues in older patients may not succeed without a better understanding of why such cells lose vitality with age. Importantly, research in this area would also help determine whether interventions that enhance cellular proliferative powers would pose an unacceptable cancer risk.

Acute inflammation is necessary for protection from invading pathogens or foreign bodies and the healing of wounds, but as we age many of us experience chronic, low-level inflammation. Such insidious inflammation is thought to be a major driver of fatal diseases of aging, including cancer, heart disease, and Alzheimer’s disease, as well as of osteoporosis, loss of lean muscle mass after middle age, anemia in the elderly, and cognitive decline after 70. Just about everything that goes wrong with our bodies as we age appears to have an important inflammatory component, and low-level inflammation may well be a significant contributor to the overall aging process itself. As the underlying mechanisms of age-related inflammation are better understood, researchers should be able to identify interventions that can safely curtail its deleterious effects beginning in mid-life, broadly enhancing later-life, and with negligible risk of side effects.

While important advances have been made toward the goal of adding healthy years to life, it cannot be achieved in a timely way without significant financial support. In stark contrast to the rapidly rising costs of healthcare for the aging, we as a Nation are making a miniscule, and declining, investment in the prevention, treatment or cure of chronic diseases of aging. Out of each dollar appropriated to NIH only 3.6 cents goes toward supporting work of the NIA. Between fiscal year 2003 and fiscal year 2010, NIA-funded scientists saw a series of nominal increases and cuts that amounted to a 14.7 percent reduction in constant dollars. The November 11, 2010 issue of *Nature* notes that “[a]lthough the funding situation is tight all around for NIH-supported investigators, the NIA is in an exceptional predicament As both the United States and global populations age, the prevalence of chronic diseases such as cancer, heart disease and diabetes will also grow, along with neurodegenerative ailments The NIA deals with age-related aspects of all of these.”

An increase in funding for aging research is urgently needed to enable scientists to capitalize on the field’s recent exciting discoveries. Advocates for age-related diseases like Alzheimer’s disease and cancer in the past have called for congressional appropriations of \$2 billion annually in order to achieve major breakthroughs in treating and curing those diseases. Thus, a goal of \$2 billion annually in Federal funding for aging research on the basic underpinnings of aging over the next 3 to 10 years seems modest considering its great potential to lower overall disease risk (including Alzheimer’s, cancer, and more) and add healthy years to life. For the NIA

in particular, an increase in funding would enable flexibility in supporting high-quality grant proposals that fall within the 20th percentile of submitted grants. In recent years, the percent of grant applications receiving funding by the NIA has dropped precipitously and currently only the top 9 percent are being funded. This means that many valuable projects are being set aside due to budget constraints, and many talented scientists who might make major contributions to aging research are being dissuaded from making this their life's work.

In addition to increased resources, the field would also benefit greatly from the creation of a trans-NIH initiative that could improve the quality and pace of research that advances the understanding of aging, its impact on age-related diseases, and the development of interventions to extend human healthspan. The initiative would be most effective if it included the representatives from the National Institute on Aging (NIA) and the major-disease focused institutes that have some role in aging research such as the National Institute of Neurological Disorders and Stroke (NINDS), National Heart, Lung, and Blood Institute (NHLBI), National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK), and the National Cancer Institute (NCI).

The field of aging research is poised to make transformational gains in the near future. Few if any areas for investing research dollars offer greater potential returns for public health. The Alliance for Aging Research supports funding the NIH at \$35 billion in fiscal year 2012 with a minimum of \$1.4 billion in funding for the NIA specifically. This level of support would allow the NIH and the NIA to adequately fund new and existing research projects, accelerating progress toward findings which could prevent, treat, slow the progression or even possibly cure conditions related to aging. With a Silver Tsunami of age driven chronic ailments looming as our population grows older, an increased emphasis on NIH's aging research activities has never been more urgent, with potential to impact so many Americans.

The payoffs from such focused attention and investment would be large and lasting. Therapies that delay aging would lessen our healthcare system's dependence on the relatively inefficient strategy of trying to redress diseases of aging one at a time, often after it is too late for meaningful benefit. They would also address the fact that while advances in lowering mortality from heart attack and stroke have dramatically increased life expectancy, they have left us vulnerable to other age-related diseases and disorders that develop in parallel, such as Alzheimer's disease, diabetes, and frailty. Properly focused and funded research could benefit millions of people by adding active, healthy, and productive years to life. Furthermore, the research will provide insights into the causes of and strategies for reducing the periods of disability that generally occur at the end of life.

Mr. Chairman, the Alliance for Aging Research thanks you for the opportunity to outline the challenges posed by the aging population that lie ahead as you consider the fiscal year 2012 appropriations for the NIH and we would be happy to furnish additional information upon request.

PREPARED STATEMENT OF THE ALLIANCE OF INFORMATION AND REFERRAL SYSTEMS

The Alliance of Information and Referral Systems (AIRS) thanks you for providing the opportunity to submit testimony as you consider an fiscal year 2012 Labor-HHS, Education Appropriations bill. AIRS is the national voice of Information and Referral/Assistance (I&R/A) services and we provide a professional umbrella for over 1,200 I&R/A providers in both public and private organizations. Our primary purpose for submitting this testimony is to urge you not to cut Title IIIB funding of the Older Americans Act (OAA) as this provides Federal funding to the States for I&R. President Obama's proposed fiscal year 2012 budget emphasizes an increase in funding of \$48 million for Title IIIB of the OAA.

Information and Referral brings people and services together. When people don't know where to turn, I&R/A is there for them. Last year, AIRS members answered more than 20 million calls for help. Comprehensive and specialized I&R/A programs help people in every community and operate as a critical component of the health and human services delivery system. I&R/A organizations have databases of programs and services and disseminate information through a variety of channels to individuals and communities. People in search of critical services such as, food, shelter, child care, work and job training, mental health support often do not know where to begin. More often than not, I&R/A organizations provide the answers.

We encourage you to support a \$48 million increase in funding for Title III of the Older Americans Act and at a very minimum, not cut funding for I&R/A services. Thank you for your consideration.

PREPARED STATEMENT OF ALLUVIAM LLC

As a small business, we're writing to you today to bring to your attention what we feel is an urgent issue regarding the National Library of Medicine (NLM) decision to enter and unfairly compete with private industry in the market for software for firefighters and other emergency responders.

It has come to our attention that NLM has been funding development of a software program ("WISER") that they then give away at no cost to first responders. Apparently, NLM has been funding this effort for the last several years; in spite of the fact that there are at least 6 other companies within this market segment that provide similar decision support tools for first responders, and have been doing so prior to NLM entering the marketplace.

Providing government funding to a program that competes with an established segment of private industry kills jobs, stifles innovation and seems inherently unfair and contrary to the long term best interest of the emergency response community and a poor use of taxpayer money. With NLM's continued practices, there will cease to be any private industry R&D, innovation or other commercial investment in this market segment, effectively killing innovative technologies like ours, and the other companies currently providing products to this market. We have attempted to raise this issue to the attention of NLM without success, even though OMB circular A-76 (revised), supra note 182 at A-3 articulates a "Red Light for On-Line and Informational Government Activity: Principle 10: The government should exercise substantial caution in entering markets in which private-sector firms are active."

We feel that NLM is acting far outside its charter as a library information service. While we certainly applaud their efforts to provide concise and useful chemical and health related information to emergency responders and the public, it seems clear that with the development of software that they then give away, NLM has crossed the line of what it has been chartered to do, and is in conflict with OMB A-76, whose basic tenets are that "in the process of governing, the Government should not compete with its citizens" and that "a commercial activity is not a governmental function." These principles provide fundamental policy direction to agencies that the Government should not be in the business of providing commercial goods and services in competition with private markets.

We've attempted to contact NLM directly, but their position has been that they are fulfilling their duty of publishing Government information. We feel that developing and distributing analytical software, running focus groups to solicit user feedback, then promoting the software at the same industry trade shows that we attend is not consistent with publishing Government data. In fact, it is quite disingenuous, as if their intent was to publish the information, they could make the information widely available in any number of portable document or html formats that would be accessible from a range of devices, from laptops to smartphones, and would not put them in direct competition with private industry.

The Government doesn't provide emergency responders free emergency response vehicles, protective clothing, respirators, radios or chemical detectors, and neither should the Government be competing with established private industry companies that are already providing decision support software to emergency responders. I'm sure that Microsoft would take umbrage with the Department of Commerce if Commerce decided to develop and then give away a free spreadsheet program simply because they thought it would benefit U.S. business.

We respectfully request that you look into defunding this NLM program and get NLM out of the business of competing with private industry for this type of software. Since NLM started promoting their software, we've had existing customers and potential clients wonder why they should pay for software that NLM makes available for free.

By way of background, as part of the Homeland Security Act of 2002, Public Law 107-296, known as the SAFETY ACT, Congress passed the Act as a mechanism to foster and support the development of innovative and effective anti-terrorism technology. Today, our company is one of a few companies in the United States that has a CBRNE/IED decision support system that has earned SAFETY ACT certification and designation as an approved anti-terrorism technology. We've spent over 5 years, and nearly 25,000 man hours—all at our own private expense, developing, fielding and deploying our technology. Today our technology, HazMasterG3® is deployed with the FBI, the Secret Service Presidential Protective Detail, every CST/WMD team in the country, the USMC's CBIRF, DHS, US Special Forces, and many civilian fire departments, HAZMAT teams and bomb squads throughout the United States.

PREPARED STATEMENT OF THE AMERICAN ACADEMY OF FAMILY PHYSICIANS

The American Academy of Family Physicians representing 97,600 family physicians, residents, and medical students nationwide, is pleased to submit this statement for the record in support of our funding priorities for inclusion in the fiscal year 2012 appropriations bill.

The AAFP urges the Senate Appropriations Subcommittee on Labor, Health and Human Services, and Education to make a robust fiscal year 2012 investment in our Nation's primary care physician workforce in order to ensure that it is adequate to provide efficient, effective healthcare delivery addressing access, quality and value.

We recognize the difficult decisions which our Nation's budgetary pressures present and remain confident that wise Federal investment will help to transform healthcare to achieve optimal, cost-efficient health for everyone. Specifically, we recommend that the Committee provide the Health Resources and Services Administration and the Agency for Healthcare Research and Quality with the fiscal year 2012 funding levels called for in the President's budget request.

Health Resources and Services Administration

HRSA is the Federal agency chiefly responsible for improving access to healthcare services for Americans who are uninsured, isolated or medically vulnerable. HRSA's mission also calls for a skilled health workforce, and the AAFP supports their efforts to train the necessary primary care physician workforce. Primary care physicians will serve as a strong foundation for a more efficient and effective healthcare system.

The AAFP recommends that the Committee provide at least \$449.5 million for all of the Health Professions Training Programs authorized by Title VII of the Public Health Service Act and administered by the Health Resources and Services Administration (HRSA) as requested in the President's fiscal year 2012 budget.

Within that line, we urge you to provide at least:

- \$140 million for Health Professions Primary Care Training and Enhancement authorized under Title VII, Section 747 of the Public Health Service Act;
- \$10 million for Teaching Health Centers development grants authorized by Title VII, Section 749A; and
- \$4 million for Title VII, Section 749B Rural Physician Training Grants.

Title VII Health Professions Training Programs

As the only medical specialty society devoted entirely to primary care, the AAFP appreciates this Committee's commitment to a strong primary care physician workforce. We are concerned that a failure to provide adequate funding for the Title VII, Section 747, the Primary Care Training and Enhancement (PCTE) program, would destabilize ongoing efforts to increase education and training support for family physicians, exacerbating primary care shortages and further straining the Nation's healthcare system.

Title VII, Section 747 primary care training grants to medical schools and residency programs have for decades helped to increase the number of physicians who select primary care specialties and work in underserved areas. A study published in the *Annals of Family Medicine* on the impact of Title VII training programs on community health center staffing and national health service corps participation found that physicians who work with the underserved in CHCs and NHSC sites are more likely to have trained in Title VII-funded programs.¹ Title VII primary care training grants are vital to departments of family medicine, general internal medicine, and general pediatrics; strengthen primary care curricula; and offer incentives for training in underserved areas.

In the coming years, medical services utilization is likely to rise given the increasing and aging population as well as the insured status of more of the populace. These demographic trends will cause primary care physician shortages to worsen. We urge the Committee to increase the level of Federal funding for primary care training to reinvigorate medical education, residency programs, as well as academic and faculty development in primary care to prepare physicians to support the patient centered medical home.

Teaching Health Centers

The AAFP has long called for reforms to graduate medical education programs in order to encourage the training of primary care residents in non-hospital settings where most primary care is delivered. An excellent first step is the innovative

¹Rittenhouse DR, et al. Impact of Title VII training programs on community health center staffing and National Health Service Corps participation. *Ann Fam Med*. 2008;6(5):397-405.

Teaching Health Centers program authorized under Title VII, Section 749A to increase primary care physician training capacity now administered by HRSA.

Federal financing of graduate medical education has led to training which occurs mainly in hospital inpatient settings in spite of the fact that most patient care is delivered outside of hospitals in ambulatory settings across the Nation. The Teaching Health Center program provides resources to any qualified community based ambulatory care setting that operates a primary care residency program including federally Qualified Health Centers or federally Qualified Health Centers Look Alikes, Rural Health Clinics, Community Mental Health Centers, a Health Center operated by the Indian Health Service, or a center receiving Title X grants.

We were pleased that the Patient Protection and Affordable Care Act authorized a mandatory appropriations trust fund of \$230 million over 5 years to fund the operations of Teaching Health Centers. However, if this program is to be effective, there must be funds for the planning grants to establish newly accredited or expanded primary care residency programs.

Rural Health Needs

Another important HRSA Title VII grant program is the Rural Physician Training Grants program to help medical schools to recruit students most likely to practice medicine in rural communities. This modest program authorized by Title VII, Section 749B will help provide rural-focused training and experience and increase the number of recent medical school graduates who practice in underserved rural communities.

National Health Service Corps

The National Health Service Corps (NHSC) recruits and places medical professionals in Health Professional Shortage Areas to meet the need for healthcare in rural and medically underserved areas. The NHSC provides scholarships or loan repayment as incentives for practitioners to enter primary care and provide healthcare to Americans in Health Professional Shortage Areas. By addressing medical school debt burdens, the NHSC also helps to ensure wider access to medical education opportunities.

The Government Accountability Office (GAO-01-1042T) described the NHSC as “one safety-net program that directly places primary care physicians and other health professionals in these medically needy areas.” Currently most of the more than 7 million people who rely on NHSC clinicians for their healthcare needs would not have access to care without the NHSC.

Since its inception in 1972, the NHSC has helped place 37,000 primary care health professionals in underserved communities across the country, many of whom remain in these areas following the completion of their service. According to the fiscal year 2009 Health Resources and Services Administration budget justification, over 75 percent of the clinicians placed by the NHSC in underserved areas continued to serve in their position for at least 1 year after the completion of their service obligation.

Today, there are over 9,000 vacancies at NHSC approved sites across the country with more added every day, yet funding is inadequate to fill all of these needed slots.

The AAFP recommends that Committee provide at least the President’s requested level of \$418.5 million for the National Health Service Corps for fiscal year 2012 to include \$295 million in funds made available for NHSC operations, scholarships and loan repayments by the Affordable Care Act.

Agency for Healthcare Research and Quality

The mission of the Agency for Healthcare Research and Quality (AHRQ)—to improve the quality, safety, efficiency, and effectiveness of healthcare for all Americans—closely mirrors the AAFP’s own mission. AHRQ is a small agency with a huge responsibility for research to support clinical decisionmaking, reduce costs, advance patient safety, decrease medical errors and improve healthcare quality and access. Family physicians recognize that AHRQ has a critical role to play in patient-centered outcomes research also known as comparative effectiveness research.

Patient-Centered Outcomes Research

AHRQ’s investment in patient-centered outcomes research will help Americans make the informed decisions we must make to focus on paying for quality rather than quantity. By determining what has limited efficacy or does not work, this important research can spare patients from tests and treatments of little value. Today, patients and their physicians face a broad array of diagnostic and treatment options without the scientific evidence needed to know what procedure or which drug is most likely to succeed or how best to time a given therapy. AHRQ is supporting re-

search to answer those questions so that physicians and their patients can make the choices about care that are most likely to succeed. AHRQ also supports the essential research into the prevention of medical errors and reducing hospital-acquired infections.

Medical Liability Demonstrations

Solving the professional medical liability has long been one of the AAFP's highest priorities. Although the medical liability demonstrations announced by AHRQ in fiscal year 2010 are quite modest, we support the effort to find alternatives to the current medical tort system.

Primary Care Extension Program

The AAFP supports the Primary Care Extension Program to be administered by AHRQ to provide support and assistance to primary care providers about evidence-based therapies and techniques so that providers can incorporate them into their practice. As AHRQ develops more scientific evidence on best practices and effective clinical innovations, the Primary Care Extension Program will disseminate them to primary care practices across the Nation in much the same way as the Federal Cooperative Extension Service provides small farms with the most current information and guidance.

The AAFP recommends that the Committee provide at least \$405 million for AHRQ in fiscal year 2012. In addition, we ask that the Primary Care Extension program receive the authorized level of \$120 million in fiscal year 2012.

PREPARED STATEMENT OF THE AMERICAN ACADEMY OF PHYSICIAN ASSISTANTS

On behalf of the nearly 80,000 clinically practicing physician assistants in the United States, the American Academy of Physician Assistants is pleased to submit comments on fiscal year 2012 appropriations for Physician Assistant (PA) educational programs that are authorized through Title VII of the Public Health Service Act.

AAPA believes that the Title VII Health Professions Programs are essential to placing health professionals in medically underserved communities. According to the Health Resources and Services Administration, an additional 301,000 healthcare practitioners are needed to alleviate existing professional shortages. One of three healthcare professions providing primary medical care in the United States, the PA profession is deemed by many economists to be among the fastest growing professions. Title VII will not only encourage greater numbers of students to enter PA educational programs; it will also help increase access to care for millions of Americans who live in medically underserved areas.

As a member of the Health Professions and Nursing Education Coalition (HPNEC), AAPA respectfully supports the coalition's request to fund Title VII health professions education program at the President's request of \$449,454,000.

AAPA recommends that Congress continue its support to grow the PA primary care work force. The U.S. healthcare system will require a much-expanded primary healthcare workforce, both in the private and public healthcare markets. For example, the National Association of Community Health Centers' March 2009 report, *Primary Care Access: An Essential Building Block of Health Reform*, predicts that in order to reach 30 million patients by 2015, health centers will need at least an additional 15,585 primary care providers, just over one-third of whom are non-physician primary care professionals.

A review of PA graduates from 1990–2009 demonstrates that PAs who have graduated from PA educational programs supported by Title VII are 67 percent more likely to be from underrepresented minority populations and 47 percent more likely to work in a rural health clinic than graduates of programs that were not supported by Title VII. Additionally, a study by the UCSF Center for California Health Workforce Studies found a strong association between physician assistants exposed to Title VII during their PA educational preparation and those who reported working in a federally qualified health center or other community health center.

Title VII programs are essential to the development and training of primary healthcare professionals and, in turn, provide increased access to care by promoting healthcare delivery in medically underserved communities. Title VII funding is especially important for PA programs as it is the only Federal funding available on a competitive application basis to these programs.

We wish to thank the members of this subcommittee for your historical role in supporting funding for the health professions programs, and we hope that we can count on your support to maintain funding to these important programs in fiscal year 2011 at the President's request.

Overview of Physician Assistant Education

Physician assistant educational programs are located within schools of medicine or health sciences, universities, teaching hospitals, and the Armed Services. All PA educational programs are accredited by the Accreditation Review Commission on Education for the Physician Assistant.

The typical PA program consists of 26 months of instruction, and the typical student has a bachelor's degree and about 4 years of prior healthcare experience. The first phase of the program consists of intensive classroom and laboratory study. More than 400 hours in classroom and laboratory instruction are devoted to the basic sciences, with over 75 hours in pharmacology, approximately 175 hours in behavioral sciences, and nearly 580 hours of clinical medicine.

The second year of PA education consists of clinical rotations. On average, students devote more than 2,000 hours, or 50 to 55 weeks, to clinical education, divided between primary care medicine—family medicine, internal medicine, pediatrics, and obstetrics and gynecology—and various specialties, including surgery and surgical specialties, internal medicine subspecialties, emergency medicine, and psychiatry. During clinical rotations, PA students work directly under the supervision of physician preceptors, participating in the full range of patient care activities, including patient assessment and diagnosis, development of treatment plans, patient education, and counseling.

After graduation from an accredited PA program, physician assistants must pass a national certifying examination developed by the National Commission on Certification of Physician Assistants. To maintain certification, PAs must log 100 continuing medical education hours every 2 years, and they must take a recertification exam every 6 years.

Physician Assistant Practice

By design, PAs always practice in teams with physicians, extending the reach of medicine and the promise of improved health to the most remote and in-need communities in our Nation. The PA profession's patient-centered, team-based approach reflects the changing realities of healthcare delivery and fits well into the patient-centered medical home model of care, as well as other integrated models of care management.

PAs practice in various medical setting across the country and in a recent survey conducted by the AAPA it is estimated that:

- Nineteen percent of all PAs practice in non-metropolitan areas where they may be the only full-time providers of care (State laws stipulate the conditions for remote supervision by a physician);
- 41 percent of PAs work in urban and inner city areas;
- 40 percent of PAs are in primary care;
- 44 percent of PAs worked in group practices or solo physician offices; and
- 80 percent of PAs practice in outpatient settings.

Nearly 300 million patient visits were made to PAs in 2009. PAs often provide autonomous medical care, have their own patient panels, and are granted prescribing authority in all 50 States.

Critical Role of Title VII Public Health Service Act Programs

Title VII programs promote access to healthcare in rural and urban underserved communities by supporting educational programs that train health professionals in fields experiencing shortages, improve the geographic distribution of health professionals, increase access to care in underserved communities, and increase minority representation in the healthcare workforce.

Title VII programs are the only Federal educational programs that are designed to address the supply and distribution imbalances in the health professions. Since the establishment of Medicare, the costs of physician residencies, nurse training, and some allied health professions training have been paid through Graduate Medical Education (GME) funding. However, GME has never been available to support PA education. More importantly, GME was not intended to generate a supply of providers who are willing to work in the nation's medically underserved communities—the purpose of Title VII.

Furthermore, Title VII programs seek to recruit students who are from underserved minority and disadvantaged populations, which is a critical step toward reducing persistent health disparities among certain racial and ethnic U.S. populations. Studies have found that health professionals from disadvantaged regions of the country are three to five times more likely to return to underserved areas to provide care.

Title VII Support of PA Educational Programs

Federal support for Title VII is authorized through section 747 of the Public Health Service Act. It is the only Federal funding available to PA educational programs. This funding is specifically targeted for primary care education and training programs and is designed to train PAs for practice in urban or rural medically underserved areas. The program is essential to the development and training of the Nation's health workforce and is critical to providing continued health services to both underserved and minority communities. It also encourages PAs to return to these environments with the greatest need after they have completed their training, being one of the best recruitment tools to date.

Title VII was last reauthorized in 2010 under the Patient Protection and Affordable Care Act. Now there is a critical need to fund the Title VII program through the appropriations process to increase the supply, diversity, and distribution of PAs and primary care practitioners in medically underserved communities.

Support for educating PAs to practice in underserved communities is particularly important given the market demand for physician assistants. Without Title VII funding to expose students to underserved sites during their training, PA students are far more likely to practice in the communities where they were raised or attended school. Title VII funding is a critical link in addressing the natural geographic maldistribution of healthcare providers by exposing students to underserved sites during their training, where they frequently choose to practice following graduation. Currently, 36 percent of PAs met their first clinical employer through their clinical rotations.

Changes in the healthcare marketplace reflect a growing reliance on PAs as part of the healthcare team. Currently, the supply of physician assistants is inadequate to meet the needs of society, and the demand for PAs is expected to increase. A 2006 article in the *Journal of the American Medical Association (JAMA)* concluded that the Federal Government should augment the use of physician assistants as physician substitutes, particularly in urban Community Health Centers (CHCs) where the proportional use of physicians is higher. The article suggested that this could be accomplished by adequately funding Title VII programs. Additionally, the Bureau of Labor Statistics projects that the number of available PA jobs will increase 39 percent between 2008 and 2018.

Title VII funding has provided a crucial pipeline of trained PAs to underserved areas. Recognizing that the PA educational programs received significantly less funding than other programs in the cluster on primary care medicine and dentistry, the 111th Congress established a 15 percent set-aside for PA education within the section 747 cluster on primary care during reauthorization of the Title VII Programs.

Recommendations on Fiscal Year 2012 Funding

The American Academy of Physician Assistants urges members of the Appropriations Committee to consider the inter-dependency of all public health agencies and programs when determining funding for fiscal year 2012. For instance, while it is critical, now more than ever, to fund clinical research at the National Institutes of Health (NIH) and to have an infrastructure at the Centers for Disease Control and Prevention (CDC) that ensures a prompt response to an infectious disease outbreak or bioterrorist attack, the good work of both of these agencies will go unrealized if the Health Resources and Services Administration (HRSA) is inadequately funded.

HRSA administers the "people" programs, such as Title VII, that bring the results of cutting edge research at NIH to patients through providers such as PAs who have been educated in Title VII-funded programs. Likewise, the CDC is heavily dependent upon an adequate supply of healthcare providers to be sure that disease outbreaks are reported, tracked, and contained.

Thank you for the opportunity to present the American Academy of Physician Assistants' views on fiscal year 2012 appropriations.

PREPARED STATEMENT OF THE AMERICAN ACADEMY OF SLEEP MEDICINE

Dear Chairman Harkin and Members of the Committee: The American Academy of Sleep Medicine (AASM), an organization composed of over 9,700 sleep care professionals and the accrediting agent for over 2,200 accredited sleep care centers, is pleased to provide our views on the HHS research budget for fiscal year 2012. As the leader in setting standards and promoting excellence in evidence-based sleep medicine healthcare, education, and research, we can attest to the fact that the work of the National Institutes of Health (NIH) has proven to be vital in allowing our members to provide effective sleep care services.

The AASM supports funding levels for the NIH that will allow the careful continuation of the current research agenda. Savings should be realized from speeding the research process, vigilant screening of new research proposals, and an honest examination of spending for ongoing research. Key criteria in reviewing ongoing research should include both the potential patient benefit and whether a stoppage today will result in a restart on some future tomorrow that will duplicate the initial research and correspondingly duplicate the previously incurred expenses.

Even in this economic climate, the value of the NIH as an incubator for advancing scientific and healthcare knowledge has to be recognized. Efforts need to be made to continue spending that: Enhances our ability to identify and provide beneficial patient care services; moves information from the white coats of the research laboratory to the white coats at the patient's bedside; and ensures a continual pipeline of research professionals.

Even with this realization, however, we are not blind to the reality of the need to pare the Federal budget. We accept the fact that the totality of NIH spending is not immune to budget cuts. The key in looking at this budget is to take steps that do not fall into the category of being unexamined cuts that are made without taking into account the repercussions of these budget-based actions. While across-the-board cuts provide a clean and arguably simple process for trimming the budget, taking a budget axe to the NIH has the very real counter-productive potential of stopping prominent, patient oriented research in mid-stream and creating a gap in the research field. These unintended consequences carry significant negative implications that our patients and our society can ill afford.

Examples of ongoing sleep related and other research recently funded by the NIH illustrate the difficulty of budget slashing that fails to take into account the three above noted bullet points. The sleep related research identified at this site (set out below) provides clear examples of ongoing research with indisputable patient care implications. This is the type of research that needs to be completed and not simply restarted at some future point with duplicated expenses. It also bears noting that the research funding on the connection between sleep apnea treatment and cardiovascular disease resulted in 12 new jobs. These are the types of jobs that build the cadre of future key researchers. The importance of this cannot go unnoticed. For the future vitality of our society, we can ill afford another "Sputnik moment" by failing to maintain the research pipeline and the personnel that are essential to its maintenance and growth.

The American Academy of Sleep Medicine urges careful consideration when addressing budget issues; the Academy is available as a resource on how those issues are connected with care for patients with sleep disorders. Please feel free to direct questions for the AASM to Bruce Blehart, Director of Health Policy and Government Relations, at BBlehart@aasmnet.org.

Nirinjini Naidoo, Ph.D.

Research Assistant Professor of Medicine, University of Pennsylvania, Philadelphia, PA

Biomarker for Sleep Loss: A Proteomic Determination

Administered by the NHLBI Division of Lung Diseases, Lung Biology and Disease Branch

Fiscal Year 2009 Recovery Act Funding: \$500,000

Additional Funding

Biomarker for Sleep Loss: A Proteomic Determination

Administered by the NHLBI Division of Lung Diseases, Lung Biology and Disease Branch

Fiscal Year 2010 Recovery Act Funding: \$500,000

Total funding: \$1,000,000

Dr. Nirinjini Naidoo grew up in South Africa, where she drew daily inspiration from her family. Her father, a classical scholar, fed the young Dr. Naidoo's desire to read voraciously. Over time, she was drawn to books about energetic, creative women in science like Marie Curie and Rosalind Franklin. "Those stories really stuck with me," Dr. Naidoo said, noting that she is intensely curious and always "wants to know." The attributes suit her well as a frontier scientist in the world of sleep research. They may be at odds with her getting sleep, though, she admitted. "I sometimes wake up at 3 a.m. and send myself an e-mail about a newly hatched experiment."

Research Focus.—Humans spend about one-third of their lives asleep. But according to Dr. Naidoo, many of us do not appreciate that sleep is a vital part of healthy living and that our bodies accomplish several important tasks during that time. "Sleep is definitely not just an 'off' state," Dr. Naidoo said. "Research is telling us that our bodies are actually very busy when we sleep—re-stocking cellular compo-

nents, consolidating memories, and strengthening connections between nerve cells in the brain.” Dr. Naidoo’s research interest in sleep came fairly recently. A chemist who specializes in studying the structures and functions of proteins, she did postdoctoral research in the area of circadian rhythms—the 24-hour cycles that tune body systems with the light-and-dark cycle of our environment. Matching her scientific skills to what she saw as a fascinating question, Dr. Naidoo decided to look at the molecular features of sleep. What proteins are talking to each other? Which genes and molecules are active . . . or asleep themselves?

Grant Close-Up.—Dr. Naidoo’s Recovery Act grant is a comprehensive search for “biomarkers” of sleep loss. Biomarkers are substances that indicate a particular state or process. They can be used to signify health problems—high cholesterol is one, for example. Or, biomarkers can denote a normal activity, like growth or sleep. But as useful as they sound, accurate biomarkers can be very difficult to find. That’s because so many factors can affect how the body functions: our diet, whether we exercise, what medicines we take, and our genetic make-up. All these components can influence body systems independently of each other, which makes finding telltale biomarkers challenging.

You could think of Dr. Naidoo’s approach as a variant on the childhood matching game “same and different.” In earlier experiments, she and other researchers identified people who were different types of sleepers. Some recovered quickly and fully from sleep deprivation and could easily pass a question-and-answer knowledge test. Others, Dr. Naidoo explained, reacted very differently and made several mistakes on the same relatively simple test. In that earlier experiment, she and leading sleep researcher Allan I. Pack, Ph.D., also at the University of Pennsylvania, collected blood samples from all the study participants. They will now use a high-tech chemical analytical tool called mass spectrometry to search for molecules that differ between the two different types of sleepers.

After 2 years, Dr. Naidoo plans to have a profile of sleepiness—a snapshot of all the proteins and other molecules in blood that define sleepy or non-sleepy. In general, biomarkers can be useful non-invasive tools for detecting illness and spotting disease risk. She hopes the sleep biomarkers will help researchers and physicians track sleep deprivation or the role of sleep loss in various diseases.

Economic Impact.—Dr. Naidoo used Recovery Act funds to buy several pieces of state-of-the-art scientific equipment, such as a powerful microscope and machines that screen blood and other fluids for their component proteins. She is especially excited about the fact that this funding is enabling her to bring new blood into the field of sleep research. “One of my new research specialists working on this project—a recent chemistry graduate—is now applying to graduate school to study sleep,” said Dr. Naidoo. “It’s so important that we get new thinking and new methods into understanding one of the most fundamental processes in our daily lives.”

By Alison Davis, Ph.D.—Last Updated: August 10, 2010

Susan Redline, M.D., M.P.H.

Professor, Case Western Reserve University, Cleveland, Ohio

PHASE II Trial of Sleep Apnea Treatment to Reduce Cardiovascular Morbidity

Administered by the NHLBI Division of Lung Diseases, National Center on Sleep Disorders Research

Fiscal Year 2009 Recovery Act Funding: \$2,190,865

Research Focus.—More than 12 million American adults have sleep apnea, a disorder where breathing repeatedly pauses or becomes shallow during sleep. The condition can double or even quadruple a person’s risk of heart disease, high blood pressure, and stroke. Despite sleep apnea’s prevalence and risks, an estimated 1 in 10 patients isn’t diagnosed or treated. One reason for the low treatment rate is that doctors lack evidence about which sleep apnea therapies actually reduce cardiovascular disease risk. On top of that, some patients who do get diagnosed may not follow through with their prescribed treatment because they think it’s uncomfortable or awkward-looking.

Grant Up Close.—Supported by an NHLBI Recovery Act funded Grand Opportunity grant, Susan Redline, M.D., M.P.H., is leading the first large-scale study in the United States to determine whether two common sleep apnea treatments reduce patients’ risk of cardiovascular disease. Her team is recruiting 1,400 cardiovascular clinic patients who have moderate to severe sleep apnea and monitoring their sleep at home.

One group of patients will receive extra oxygen at night. Dr. Redline wants to know if this simple therapy reduces the health risks of sleep apnea by compensating for lost breaths, or raises the risks by not increasing patients’ breath rates. A second group of patients will receive another common sleep apnea treatment, continuous positive airway pressure (CPAP), in which a machine blows air into the throat each

night through a mask worn over the nose and mouth. Although both CPAP and oxygen therapy are widely used, researchers haven't yet established whether using them to treat sleep apnea reduces cardiovascular disease risk. Dr. Redline's team will conduct comparative effectiveness research into the two treatments. A third group of patients will not undergo sleep apnea treatment.

All three groups will have their early signs of cardiovascular disease treated. Together, these groups will help Dr. Redline's team begin to determine whether treating sleep apnea can change patients' risk of cardiovascular disease. The results of the study will also set the stage for advanced clinical trials. Her goal is to help doctors integrate sleep medicine into routine cardiology care and develop evidence-based treatment guidelines, ultimately lowering deaths from sleep apnea-related heart disease.

"A true multidisciplinary team".—The study includes cardiologists and sleep medicine experts from four sites across the country. Some of them already collaborate through the NHLBI's Sleep Heart Health Study, a multi-center population study examining the cardiovascular effects of sleep apnea. "My colleagues include engineers, informaticians, physiologists, geneticists, epidemiologists and clinicians," said Dr. Redline. "I meet regularly with these diverse and talented people to review our common or overlapping goals."

Economic Impact.—Thanks to Recovery Act funds, the team was able to create 12 new jobs. They also bought new equipment, including portable devices to measure patients' blood pressure and other responses to sleep apnea treatments. Because the trial involves several sites, the team developed an advanced web-based data management platform. Researchers beyond the study can adapt it to their own needs so they can start new studies faster and manage them more efficiently.

Broadening her Dream.—"As a child, I wanted to be a general physician, with a shingle on my door, and simply help people feel better," said Dr. Redline. She was accepted into an accelerated 6-year medical honors program when she was just 15 years old. Then her dream began to evolve. "As I was exposed to academic medicine and powerful epidemiological methods, I realized that I wanted to work on broad issues that impact the health of the community, especially the underserved," she said. Learning about how the environment can impact people's lung health, and seeing how common but poorly understood sleep disorders were, Dr. Redline decided that researching sleep medicine was the way she could help improve public health.

Outside the Lab.—Dr. Redline likes to spend time reading, biking, and kayaking.

Aiming High.—Dr. Redline wants to find a practical treatment for sleep apnea that improves people's sleep quality and lowers their risk of heart disease; and to uncover genes that contribute to sleep apnea, so researchers can develop better targeted treatments.

By Stephanie Dutchen—Last Updated: August 10, 2010.

PREPARED STATEMENT OF THE AMERICAN ASSOCIATION FOR CANCER RESEARCH

The American Association for Cancer Research (AACR) is the world's oldest and largest scientific organization focused on every aspect of high-quality, innovative cancer research. The mission of the AACR and its more than 33,000 members is to prevent and cure cancer through research, education, communication and collaboration. We thank the United States Congress for its longstanding, bipartisan support for the National Institutes of Health (NIH) and for its commitment to funding cancer research.

The AACR urges the Senate to continue this commitment to NIH in the coming fiscal year. To sustain the momentum generated through past investments in biomedical research and to improve the health of all Americans, the AACR recommends \$35 billion for the NIH, including \$5.795 billion for the National Cancer Institute (NCI) in fiscal year 2012. This level of funding is needed to sustain the momentum generated through regular appropriations and the additional funds from the American Recovery and Reinvestment Act of 2009.

Cancer research saves lives

The Nation's historical investment in cancer research is unquestionably having a remarkable impact. We are in a time of unprecedented scientific opportunity: we are now able to accelerate progress against cancer by translating a wealth of scientific discoveries, such as the mapping of the human genome, into new treatments and preventive strategies for cancer. We can continue to make significant advances—but only if we continue to allocate the required resources to do so. Reversing recent cuts and providing stable, increased funding will greatly aid a full-scale national effort to lessen the burden of the more than 200 diseases we collectively call cancer.

This year marks the 40th anniversary of the enactment of the National Cancer Act. In the four decades since President Richard M. Nixon signed this landmark legislation: Annual cancer death rates in the United States have declined steadily; the 5-year survival rate for all cancers combined has improved to more than 65 percent; the 5-year survival rate for all childhood cancers combined has increased from 30 percent in 1976 to 80 percent today; and 12 million Americans have become cancer survivors, compared with only 3 million in 1971.

These remarkable achievements are a direct result of our national commitment to funding cancer research, screening, and treatment programs at the NCI, NIH, and other agencies across the Federal Government. Yet this substantial progress will be slowed if the Federal commitment to funding for critical cancer research priorities is not maintained.

In the last 40 years, innumerable advances in basic science, cancer prevention and detection, therapeutic development and clinical cancer management have been achieved. While these advances are too numerous to list here, the following cancer research advancements occurred in 2010 alone, as a direct result of funding by the NIH:

- 12 new cancer drugs or cancer drug uses were approved by the FDA, including the first-ever therapeutic vaccine, Provenge, which was approved for men with metastatic prostate cancer; and
- biological knowledge of tumor genes and the tumor microenvironment has led to the development of drugs that inhibit specific genetic targets, which may result in new treatments for multiple types of cancers, including melanoma and lymphoma.

The opportunities and the science currently underway promise many more successes in improved treatment and prevention of cancer. Currently, there are: More than 800 cancer therapies from industry in some step of the trial process; more than 2,000 clinical trials accepting children and young adults in progress; and more than 200 cancer prevention trials open.

Right now, we are facing a precipice with cancer. The biological knowledge and the technological advances have positioned scientists at an inflection point. To pull back from Federal investment is to abandon science in a time when scientists will be able to make quantum leaps in prevention and treatment of cancer. It is imperative that sustained appropriations be provided to the NIH so that these opportunities and other promising areas such as personalized medicine and cancer prevention do not slip from our grasp.

Cancer remains a significant public health challenge

We have made significant progress against cancer in recent years, but as long as cancer remains the leading cause of death for Americans under age 85 and the second-leading cause of death overall, we cannot afford to slow down. In 2011, 1.5 million new cancer cases will be diagnosed and more than half a million American lives will be lost to this terrible collection of diseases.

Moreover, the United States is facing what some have termed a “cancer tsunami” as the baby boom generation reaches age 65 this year. More than three-quarters of all cancers are diagnosed in individuals aged 55 and older, and the number of cancer cases is estimated to approach 2 million new cases per year by 2025. This will dramatically exacerbate the current problems with the healthcare system and it will undoubtedly hit those who can least afford it—elderly, medically underserved, and minority populations—the hardest.

Beyond the enormous toll cancer takes on the lives of affected individuals and their loved ones, cancer places a heavy burden on the U.S. economy, costing an estimated \$228 billion in direct medical costs and indirect costs associated with lost productivity due to illness and premature death.

Targeted therapies as the future of cancer treatment

The future of cancer treatment lies in the ability to treat patients based on the specific characteristics of a patient and his or her cancer—often referred to as personalized medicine. Cancer research is leading the way toward the realization of personalized medicine, in no small part thanks to Federal investment in deciphering the fundamental biology of cells, such as the Human Genome Project and, more recently, The Cancer Genome Atlas, an NCI project that is identifying important genetic changes involved in cancer.

The NCI is investing in efforts that will facilitate the translation of this wealth of basic knowledge into new treatments, including validating cancer biomarkers for prognosis, metastasis, treatment response, and progression; accelerating the identification and validation of potential cancer molecular targets; minimizing the

toxicities of cancer therapy; and integrating the clinical trial infrastructure for speed and efficiency.

Accelerating progress in cancer prevention

The AACR has long been a supporter of cancer prevention research aimed at identifying effective strategies to prevent cancer through lifestyle changes, chemoprevention, and early detection and treatment. Prevention is the keystone to success in the battle against cancer because preventing the disease is far more desirable—and cost-effective—than treating it. More than half of all cancers are related to modifiable behavioral factors, including tobacco use, diet, physical inactivity and sun exposure. Furthermore, many cancers can be halted in the early stages if individuals have access to, and take advantage of, screening tests. Vaccination—one of the most successful approaches for preventing disease—is one of the most promising areas of ongoing cancer prevention research.

Research on cancer prevention at the NCI focuses on three main areas: Risk assessment, including understanding and modifying lifestyle factors that increase cancer risk; developing medical interventions (chemoprevention), such as drugs or vaccines, to prevent or disrupt the carcinogenic process; and developing early detection and screening strategies that result in the identification and removal of precancerous lesions and early-stage cancers.

Cancer biology intersects with several areas and disciplines of cancer prevention, pointing to opportunities for, and the importance of, integrative, interdisciplinary efforts to advance clinical cancer prevention through hard-won science. The breadth and excitement of these current opportunities have never been greater.

Addressing and conquering cancer health disparities

Certain minority and underserved population groups continue to suffer disproportionately from cancer. Conquering cancer health disparities will contribute significantly to reducing the Nation's overall cancer burden, and this issue has been an important focus of both the NCI and the AACR. The NCI's investments in this area include: studying the factors that cause cancer health disparities; working with underserved communities to develop targeted interventions; developing the knowledge base for integrating cancer services to the underserved; collaborating to implement culturally appropriate information and dissemination approaches to underserved populations; and examining the role of health policy in eliminating cancer health disparities.

One size does not fit all in cancer treatment and prevention—certain populations may require specialized approaches to achieve success. We must make every effort to reduce and equalize cancer rates across all populations. The AACR urges sustained funding for these programs to ensure that all people benefit from cancer research and that these disparities are eliminated.

Fighting cancer in challenging fiscal times

We are acutely aware of the difficult decisions Congress must make as it seeks to improve the Nation's fiscal stability. However, it is imperative that such efforts be grounded in the goal of securing the prosperity and well-being of the American people. It is not by chance that the United States is the world leader in cancer research and the development of lifesaving treatments. Our preeminence is a direct result of the steadfast determination of the American public and the U.S. Congress to reduce the burden of this devastating disease by supporting and investing in research through the NIH and NCI.

Consider the following:

- Biomedical research is essential to maintaining American global competitiveness. While our Nation has been the undisputed leader in research and innovation, other countries are catching up. According to the Organisation for Economic Co-operation and Development (OECD), national expenditures for research and development as a percentage of gross domestic product (GDP) remained static for the United States between 2001 and 2008 while growing nearly 60 percent in China and 34 percent in South Korea. If this trend continues, we risk losing our global preeminence in biomedical research.
- Biomedical research has a strong positive impact on State and local economies. NIH dollars are creating and preserving high-wage, high-tech jobs at a critical time for the U.S. economy. A recent report issued by United for Medical Research estimated that in fiscal year 2010, NIH awards led to the creation of 488,000 jobs across the country, producing \$68 billion in new economic activity. The NCI alone funds more than 6,500 research grants at more than 150 cancer centers and specialized research facilities located in 49 States. In over half the States, grants and contracts to institutions exceed \$15 million annually.

—Biomedical research is an effective and efficient use of public dollars. NIH funding does not stay inside the Beltway. More than 80 percent of the dollars appropriated to the NIH are distributed throughout the United States to research projects that have undergone rigorous review for scientific merit. NIH has consistently received the highest possible ranking of “effective” under the Office of Management and Budget’s Program Assessment Rating Tool (PART), demonstrating that its programs set ambitious goals, achieve results, and are well-managed and efficient.

Recent cuts to the NIH jeopardize scientific progress

The \$320 million in cuts to the NIH enacted in the full-year continuing appropriations of 2011, which included \$45 million in cuts to the NCI, will yield harmful consequences for cancer research and cancer patients. This loss of funding will result in the following: a 10 percent reduction in the number of new grants that can be awarded this year; a 3 percent cut to existing grants; and as much as a 5 percent cut to funding for NCI-designated cancer centers. These cuts mean that success rates for grants could fall into the single digits, leaving numerous meritorious grant proposals, which could be the key to new therapies, unfunded at a time of unprecedented scientific opportunity. Furthermore, cancer centers and research laboratories may have to lay off workers as a result of reduced funding, which would negatively impact local economies across the Nation. Budget cuts and low success rates for grant proposals also discourage young scientists from entering the field, putting the future scientific workforce at risk.

The NIH needs stable, predictable increases in funding

Although cancer remains a costly burden in terms of its human and economic toll, previous investments have led to an abundance of promising research opportunities, and it is crucial that such possibilities are not lost. We thank Congress for its past support for the NIH and cancer research and urge Congress to continue its long-standing, bipartisan commitment. The American people are depending on Congress to ensure the Nation does not lose the health and economic benefits that result from our extraordinary commitment to medical research. The AACR looks forward to working with you to assure that our collective commitment to ending the pain and suffering inflicted by cancer is upheld and that researchers have the resources needed to continue to deliver hope and tangible progress.

PREPARED STATEMENT OF THE AMERICAN ASSOCIATION FOR DENTAL RESEARCH

Introduction

Mr. Chairman and Members of the Subcommittee, I am Jeff Ebersole, Director of the Center for Oral Health Research at the University of Kentucky College of Dentistry. My testimony is on behalf of the American Association for Dental Research, where I currently serve as President.

I thank the Subcommittee for this opportunity to testify about the exciting advances in oral health science. With the support of this Committee, the research funded by the National Institute of Dental and Craniofacial Research (NIDCR) has not only returned dividends in terms of improvements in oral health across the U.S. population, but also in a wide array of other health issues ranging from craniofacial birth defects to chronic orofacial pain to oral cancer. The investments we make today will create an exciting tomorrow for the treatment and prevention of oral health diseases and disorders.

What is the American Association for Dental Research?

The American Association for Dental Research is headquartered in Alexandria, Virginia. It is a nonprofit organization with more than 4,000 members in the United States. Its mission is to: (1) advance research and increase knowledge for the improvement of oral health; (2) support and represent the oral health research community; and (3) facilitate the dissemination and application of research findings. The AADR is the largest Division of the International Association for Dental Research.

Why is Oral Health Important?

Oral health is an essential component of health across the lifespan. Poor oral health and untreated oral diseases and conditions can have a significant impact on social development, economic accomplishment, and the quality of life. They can affect the most basic human needs including the ability to eat and drink, swallow, maintain proper nutrition, smile and communicate.

Over the past 50 years, there has been a dramatic improvement in oral health. Still oral diseases remain a major concern. Tooth decay and gum disease represent

the predominant infections facing the public, although complete tooth loss, oral cancer, trauma to the mouth, and congenital facial anomalies also contribute to the ongoing importance of oral health research and care.

Employed adults in the United States lose more than 164 million hours of work each year as a result of oral health problems and children are estimated to lose 54 million school hours.¹ Approximately 25 percent of adults over the age of 60 have lost all of their natural teeth.² Americans with the poorest oral health are usually those who are economically disadvantaged, lack insurance, or are members of racial and ethnic minorities. Moreover, as the Nation ages oral health issues, particularly gum disease and the oral health impact of medical treatments and medicines will continue to increase.

Research Accomplishments

Salivary Diagnostics.—For many decades researchers have known that saliva is important for more than chewing, tasting, swallowing, and as the first step in digestion. A multitude of proteins and other molecules in saliva also play vital roles in protecting us from bacteria and viruses that are constantly entering through the mouth and can cause disease.

Now, scientists are well on their way to understanding how saliva contributes to broader health functions. In 2008, an NIDCR supported team of biologists, chemists, engineers and computer scientists at five research institutions across the country mapped the salivary proteome—a “catalogue and dictionary” of proteins present in human saliva.

This saliva database is an important first step toward being able to use biomarkers in saliva to diagnose or predict oral and systemic diseases. Saliva tests based on these biomarkers offer many advantages over blood tests that require a needle stick and can pose contamination risks from blood-borne diseases. However, much effort is still required. It is crucial that the research community have the resources necessary to refine and enrich the “dictionary” of proteins present in human saliva. Saliva tests could prove to be a potentially lifesaving alternative to detect diseases where early diagnosis is critical— as in the case of oral cancer or heart attacks.

Oral Cancer.—Oral cancer affects approximately 38,000 Americans each year. Oral cancer is any cancerous tissue growth located in the mouth. The death rate associated with this cancer is especially high due to delayed diagnosis. Only 60 percent of those with this cancer will survive more than 5 years.

Researchers are developing a Point of Care diagnostic system (real-time) for rapid onsite detection of saliva-based tumor markers. Early detection of oral cancer will increase survival rates, improve the quality of care for patients, and it will result in a significant reduction in healthcare costs.

Resources must be available to permit researchers to complete work on the Point of Care diagnostic systems, and to develop new therapeutic approaches. It should also be noted that several new drug candidates are now becoming available to treat oral cancer. It is believed that at least one of these drugs will be ready for FDA approval in the very near future.

Health Disparities.—Health Disparities are the persistent gaps between the health status of minorities and non-minorities in the United States. Predicted causes of health disparities are related to educational, socioeconomic, and environmental characteristics of different ethnic and racial groups, and most recently recognized in historically underserved rural populations of the United States.

The NIDCR is one of the leading institutes at NIH supporting health disparities research. The program at NIDCR takes a multidisciplinary approach to solving the complex problem of health disparities by addressing it from a holistic health perspective. The institute funded investigations engage behavioral and social scientists, health policy experts, economists, and basic and clinical dental and medical researchers. NIDCR has supported new health centers which focus on numerous populations at risk, including African Americans, Hispanic/Latinos, Native Americans and rural communities. The centers partner with other academic health centers, State and local health agencies, community and migrant health centers, and institutions that serve these targeted populations.

The physical and economic burden due to health disparities is real and efforts must continue in order to eliminate them. I am proud to say that dental researchers are leading this charge.

¹ Centers for Disease Control Publication, “Oral Health for Adults,” December 2006.

² Ibid.

Conclusion

As you can see Mr. Chairman, much has been accomplished with the resources provided by this committee; however, there is much yet to be done. Science is advancing rapidly and the next generation of technological innovation may greatly accelerate the next breakthroughs in oral, dental and craniofacial research. Researchers have already created prototypes for “labs-on-a-chip,” bioengineered tissue replacements, and developed powerful molecular imaging tools that provide a new window into complex biological systems about which we continue to learn. This emerging wave of knowledge and tools will accelerate the development of molecular-based oral healthcare. As importantly, the NIDCR provides the resources for training the next generation of biomedical scientists focusing on oral health issues as well as the future academics to train the next generation of dentists for the United States. Thus, it is vital that NIDCR have the resources to support a diverse portfolio of research and training. The AADR representing each of these constituencies respectfully requests a fiscal year 2012 budget of \$468 million for NIDCR.

Thank you.

PREPARED STATEMENT OF THE AMERICAN ASSOCIATION FOR GERIATRIC PSYCHIATRY

The American Association for Geriatric Psychiatry (AAGP) appreciates this opportunity to comment on issues related to fiscal year 2012 appropriations for mental health research and services. AAGP is a professional membership organization dedicated to promoting the mental health and well-being of older Americans and improving the care of those with late-life mental disorders. AAGP's membership consists of geriatric psychiatrists as well as other health professionals who focus on the mental health problems faced by aging adults. Although we generally agree with others in the mental health community about the importance of sustained and adequate Federal funding for mental health research and treatment, AAGP brings a unique perspective to these issues because of the elderly patient population served by our members.

A National Health Crisis: Demographic Projections and the Mental Disorders of Aging

The aging of the baby boomer generation will result in an increase in the proportion of persons over 65 from 12.7 percent currently to 20 percent in 2030, with the fastest growing segment of the population consisting of age 85 and older. During the same period, the number of older adults with major psychiatric illnesses will more than double, from an estimated 7 million to 15 million individuals, meeting or exceeding the number of consumers in discrete, younger age groups.

Center for Mental Health Services

It is critical that there be adequate funding for the mental health initiatives under the jurisdiction of the Center for Mental Health Services (CMHS) within the Substance Abuse and Mental Health Services Administration (SAMHSA). While research is of critical importance to a better future, today's patients must also receive appropriate treatment for their mental health problems.

Evidence-based Mental Health Outreach and Treatment for the Elderly

AAGP was pleased that the final budgets for the last 9 years have included \$5 million for evidence-based mental health outreach and treatment to the elderly, the only federally funded services program dedicated specifically to the mental healthcare of older adults. AAGP is concerned that this program was eliminated in the President's fiscal year 2012 budget proposal. It is critical that SAMHSA and CMHS ensure that, as they design programs to promote prevention and recovery from mental illness, the senior citizen cohort not be ignored. AAGP asks the Committee to restore the funding for this critical program as well as ensure that all of CMHS's programs assure a life-span approach by specifically including the older adult population as a targeted population.

Centers of Excellence for Depressive and Bipolar Disorders

PPACA also included authorization for a new national network of centers of excellence for depressive and bipolar disorders, which will enhance the coordination and integration of physical, mental and social care that are critical to the identification and treatment of depression and other mental disorders across the lifespan. The work of these centers will help to disseminate and implement evidence-based practices in clinical settings throughout the country. AAGP strongly supports funding for the centers authorized by this legislation and is disappointed that the Administration has not recommended funding them. With respect to older adults, these cen-

ters would be able to focus on new models of care that integrate evidenced-based depression care into real world primary care and home care to improve the outcomes; specific combinations of medications and talk therapy that successfully treat depression and prevent relapse in older adults; specific clinical and biological factors that link depression and risk of Alzheimer's disease in some older depressed patients; and prevention of depression in older people at risk. AAGP recommends that these centers be funded at \$10 million for fiscal year 2012.

Preparing a Workforce to meet the Mental Health Needs of the Aging Population

In 2008, the Institute of Medicine (IOM) released a study of the readiness of the Nation's healthcare workforce to meet the needs of its aging population. The Re-tooling for an Aging America: Building the Health Care Workforce called for immediate investments in preparing our healthcare system to care for older Americans and their families. AAGP is deeply grateful to this subcommittee and its House counterpart for providing, in the appropriations bill for fiscal year 2010, funding for a follow-up study of the current and projected mental and behavioral healthcare needs for aging Americans. This study, which is now underway, will complement the 2008 IOM study in providing in-depth consideration of the mental health needs of geriatric and ethnic minority populations that were precluded by the broad scope of the earlier one.

Virtually all healthcare providers need to be fully prepared to manage the common medical and mental health problems of old age. In addition, the number of geriatric health specialists, including mental health providers, needs to be increased both to provide care for those older adults with the most complex issues and to train the rest of the workforce in the common medical and mental health problems of old age. The small numbers of specialists in geriatric mental health, combined with increases in life expectancy and the growing population of the Nation's elderly, foretells a crisis in healthcare that will impact older adults and their families nationwide.

Already, there are programs administered by the Bureau of Health Professions in the HHS Health Resources and Services Administration (HRSA) administers that are aimed to help to assure adequate numbers of healthcare practitioners for the Nation's geriatric population, especially in underserved areas. These are the only Federal programs that seek to increase the number of faculty with geriatrics expertise in a variety of disciplines, and the breadth of the programs has been strengthened by provisions included in the Patient Protection and Affordable Care Act (PPACA).

The geriatric health professions program supports these important initiatives:

- The Geriatric Education Center (GEC) program provides interdisciplinary training for healthcare professionals in assessment, chronic disease syndromes, care planning, emergency preparedness, and cultural competence unique to older Americans. PPACA authorizes \$10.8 million in supplemental grants for the GEC Program to support training in geriatrics, chronic care management, and long-term care for faculty in a broad array of health professions schools, as well as direct care workers and family caregivers. GECs receiving these grants are required to develop and include material on depression and other mental disorders common among older adults, medication safety issues for older adults, and management of the psychological and behavioral aspects of dementia in all appropriate training courses.
- The Geriatric Training for Physicians, Dentists, and Behavioral and Mental Health Professionals (GTPD Program) provides fellows with exposure to older adult patients in various levels of wellness and functioning and from a range of socioeconomic and racial/ethnic backgrounds.
- The Geriatric Academic Career Awards (GACA) support the academic career development of geriatric specialists in junior faculty positions who are committed to teaching geriatrics in professional schools. PPACA expands the disciplines eligible for the awards. GACA recipients are required to provide training in clinical geriatrics, including the training of interdisciplinary teams of healthcare professionals.
- PPACA authorized a new Geriatric Career Incentive Awards Program in Title VIII of the Public Health Service Act for grants to foster great interest among a variety of health professionals in entering the field of geriatrics, long-term care, and chronic care management. This program was authorized for \$10 million over 3 years.
- A new program, authorized by PPACA at \$10 million for 3 years, will provide advanced training opportunities for direct care workers in the field of geriatrics, long term-care or chronic care management.

AAGP strongly supports increased funding for the existing programs, particularly as the disciplines included have been expanded, and funding to fully authorized levels for the new programs.

National Institutes of Health (NIH) and National Institute of Mental Health (NIMH)

With the graying of the population, mental disorders of aging represent a growing crisis that will require a greater investment in research to understand age-related brain disorders and to develop new approaches to prevention and treatment. Even in the years in which funding was increased for NIH and the NIMH, these increases did not always translate into comparable increases in funding that specifically address problems of older adults. For instance, according to figures provided by NIMH, NIMH total aging research amounts decreased from \$106,090,000 in 2002 to \$85,164,000 in 2006 (dollars in thousands: \$106,090 in 2002, \$100,055 in 2003, \$97,418 in 2004, \$91,686 in 2005, \$85,164 in 2006).

The critical disparity between federally funded research on mental health and aging and the projected mental health needs of older adults is continuing. If the mental health research budget for older adults is not substantially increased immediately, progress to reduce mental illness among the growing elderly population will be severely compromised. While many different types of mental and behavioral disorders occur in late life, they are not an inevitable part of the aging process, and continued and expanded research holds the promise of improving the mental health and quality of life for older Americans. This trend must be immediately reversed to ensure that our next generation of elders is able to access effective treatment for mental illness. Federal funding of research must be broad-based and should include basic, translational, clinical, and health services research on mental disorders in late life.

AAGP believes that it is critical that NIH begin to invest increased funding in future evidence-based treatments for our Nation's elders. Annual increases of funds targeted for geriatric mental health research at NIH should be used to: (1) identify the causes of age-related brain and mental disorders to prevent mental disorders before they devastate lives; (2) speed the search for effective treatments and efficient methods of treatment delivery; and (3) improve the quality of life for older adults with mental disorders.

Participation of Older Adults in Clinical Trials

Federal approval for most new drugs is based on research demonstrating safety and efficacy in young and middle-aged adults. These studies typically exclude people who are old, who have more than one health problem, or who take multiple medications. As the population ages, that is the very profile of many people who seek treatment. Thus, there is little available scientific information on the safety of drugs approved by the Food and Drug Administration (FDA) in substantial numbers of older adults who are likely to take those drugs. Pivotal regulatory trials never address the special efficacy and safety concerns that arise specifically in the care of the Nation's mentally ill elderly. This is a critical public health obligation of the Nation's health agencies. Just as the FDA has begun to require inclusion of children in appropriate studies, the agency should work closely with the geriatric research community, healthcare consumers, pharmaceutical manufacturers, and other stakeholders to develop innovative, fair mechanisms to encourage the inclusion of older adults in clinical trials. Clinical research must also include elders from diverse ethnic and cultural groups. In addition, AAGP urges that Federal funds be made available each year for support of clinical trials involving older adults.

Study on NIH Funding for Mental Disorders among Older Adults

As little emphasis has been placed on the development of new treatments for geriatric mental disorders, AAGP encourages NIH to promote the development of new medications specifically targeted at brain-based mental disorders of the elderly. AAGP urges this Committee to request a GAO study on spending by NIH on conditions and illnesses related to the mental health of older individuals. NIH is already working to enhance cooperative activities among NIH Institutes and Centers that support research on the nervous system. A GAO study of the work being done by these institutes in areas that predominately involve older adults could provide crucial insights into possible new areas of cooperative research, which in turn will lead to advances in prevention and treatment for these devastating illnesses.

Conclusion

AAGP recommends:

- Increased funding for the geriatric health professions education programs under Title VII of the Public Health Service Act and full funding for new programs authorized by the PPACA;

- Funding to support clinical trials involving older adults;
- A GAO study on spending by NIH on conditions and illnesses related to the mental health of older individuals;
- \$5 million in funding to continue evidence-based geriatric mental health outreach and treatment programs at CMHS;
- \$10 million in funding for Centers of Excellence for Depressive and Bipolar Disorders.

PREPARED STATEMENT OF THE AMERICAN ASSOCIATION OF COLLEGES OF NURSING

The American Association of Colleges of Nursing (AACN) respectfully submits this testimony highlighting funding priorities for nursing education and research programs in fiscal year 2012. AACN represents 667 schools of nursing with baccalaureate and graduate nursing programs that educate over 337,000 students and employ more than 15,000 full-time faculty members. These institutions educate approximately half of our Nation's Registered Nurses (RNs) and all of the Advanced Practice Registered Nurses (APRNs), nurse faculty, and researchers.

The programs outlined in this testimony play an integral role in continuing to shape, advance, and promote a professional nursing workforce to meet the needs of America's patients. An emphasis on two key components of the profession—education and research—will be necessary to sustain and enhance the quality of nursing care in the United States. The release of the landmark Institute of Medicine's (IOM) report, *The Future of Nursing: Leading Change, Advancing Health*, outlines specific priorities for the profession and identifies expanded Federal support to meet the goals of preparing a more highly educated nursing workforce, removing barriers so all nurses can practice to the full scope of their education, and enabling nurses to serve as equal partners in the redesign of the healthcare system.

The ongoing reform of our healthcare system will continue to increase access to care, requiring a surge in the number of nurses and other health professionals. RNs and APRNs will be in high demand given the needs of an aging population, the increased complexity of care, and significant growth in the number of patients with chronic diseases. More specifically, the U.S. Bureau of Labor Statistics projects a demand on our delivery system that will necessitate the creation of 581,000 new positions by 2018, a 22 percent increase in the nursing workforce. Without increased attention to the challenges facing nursing education, schools of nursing will be unable to meet this demand, further jeopardizing access to quality care.

The current supply and demand of nurses demonstrates two distinct challenges. First, due to the present and looming need for healthcare by American consumers, the supply of nurses is not growing at a pace that will adequately meet long-term projections, including the demand for primary care provided by APRNs. This issue is further compounded by the number of nurses who will retire or leave the profession in the near future, ultimately reducing the nursing workforce. Currently, over 1 million of the total 2.6 million practicing nurses are over the age of 50. More striking yet, over 275,000 RNs are over the age of 60 according to the 2008 National Sample Survey of Registered Nurses.

Second, the supply of nurses nationwide is stretched thin due, in large part, to capacity barriers in schools of nursing. According to AACN, 67,563 qualified applications were turned away from baccalaureate and graduate nursing programs in 2010, primarily due to budget constraints which impact the insufficient number of faculty, clinical sites, classroom space, and clinical preceptors. As the ability of most States to support the needs of higher education has decreased, Federal support for nursing education has become even more critical. National reform goals cannot be met without an adequate number of nurses to provide the cost-effective and quality care associated with the nursing discipline.

NURSING WORKFORCE DEVELOPMENT PROGRAMS: A PROVEN SOLUTION

For nearly 50 years, the Title VIII Nursing Workforce Development Programs (42 U.S.C. 296 et seq.) have supported hundreds of thousands of nurses and nursing students. Between fiscal year 2006 and 2009, the Title VIII programs supported over 347,000 nurses and nursing students as well as numerous academic nursing institutions and healthcare facilities. As the largest source of dedicated funding for nursing, the Title VIII programs award grants to nursing education programs, as well as provide direct support through loans, scholarships, traineeships, and programmatic grants. The programs also favor institutions that educate nurses for practice in rural and medically underserved communities and help to develop a more diverse nursing workforce to meet the cultural healthcare needs of our Nation's population. Additionally, programs funded through Title VIII contribute to the

promotion of academic progression, a major goal highlighted in the IOM's Future of Nursing report.

Of specific interest to AACN, the Title VIII programs support future nurse faculty, a significant barrier to addressing the nursing care needs in the United States. The nurse faculty shortage has grown critical as the national vacancy rate is 6.9 percent for schools offering baccalaureate and graduate nursing programs according to an AACN Survey on Vacant Faculty Positions for Academic Year 2010–2011. Of those schools reporting vacancies, the number of positions left unfilled was 803. Regionally, schools of nursing are struggling to recruit and hire faculty. Compared to the North Atlantic (9.2 percent), Southern (9.5 percent), and Mid-Western (9.2 percent) regions of the country, the West Coast (11.7 percent) has the highest faculty vacancy rate.

Title VIII Effectiveness

The Nursing Workforce Development Programs are effective and meet their authorized mission. AACN's 2010–2011 Title VIII Student Recipient Survey included responses from 1,459 students who noted that these programs played a critical role in funding their nursing education, which will ultimately help them to achieve future career goals. The students responding to the Title VIII survey have career aspirations that meet the direct needs of the healthcare system and the profession. Nearly one-third (32.8 percent) of the respondents reported that their career goal is to become a nurse practitioner. Given the demand for primary care providers, the Title VIII funds are helping to support the next generation of these essential practitioners. Moreover, the nurse faculty shortage continues to inhibit the ability of nursing schools to increase student capacity. Of the students who responded to the survey, an additional 33.2 percent stated their ultimate career goal was to become nurse faculty. Providing support for Title VIII is the key to help schools expand student capacity, fill vacant nursing positions, and, in turn, improve healthcare quality.

Demand for Title VIII

While millions of Americans are struggling during this economic downturn and thousands of students need loans to finance their education, Federal support is necessary. Nursing students depend on Federal loans like Title VIII to pay for their education. AACN's Title VIII Student Recipient Survey also indicated that 73 percent of the undergraduate and 62.6 percent of the master's students responding to the question regarding funding for nursing education noted that they will pay for their education through Federal loans. The average loan amount that students reported they would take (private/Federal) to support their education was \$19,336 for undergraduate students and \$55,698 for master's students. These students also noted that the total amount they will pay for their education is \$32,307 for undergraduates and \$64,734 for master's. Given this information, it is interesting to note that 65.6 percent of the students reported that the amount of support they received from Title VIII was \$3,000 or less in one fiscal year.

Over the last 47 years, Congress has used the Title VIII authorities as a mechanism to address past nursing shortages. When the need for nurses was great, such as in the 1970s, appropriations were higher. Congress provided \$160.61 million to the Title VIII programs in 1973. Adjusting for inflation, \$160.61 million in 1973 dollars would be equivalent to \$841.371 million in 2011 dollars. The fiscal year 2011 investment of \$242.387 million represents a 70 percent reduction in buying power for the Title VIII programs, at a time when our Nation faces historic demands on our nursing workforce.

AACN respectfully requests \$313.075 million for the Nursing Workforce Development Programs authorized under Title VIII of the Public Health Service Act in fiscal year 2012 as recommended in the President's budget proposal.

NURSING RESEARCH: SUPPORTING HEALTH PROMOTION AND DISEASE PREVENTION

The National Institute of Nursing Research (NINR) is one of the 27 Institutes and Centers at the National Institutes of Health (NIH). As the Nation's nucleus for nursing science, NINR funds research that establishes the scientific basis for health promotion, disease prevention, and high quality nursing care to individuals, families, and populations. Often working collaboratively with physicians and other researchers, nurse scientists are vital in setting the national research agenda. NINR focuses on four strategic areas which include promoting health and preventing disease, eliminating health disparities, improving quality of life, and setting directions for end-of-life research.

NINR's fiscal year 2011 funding level of \$144.381 million is approximately 0.47 percent of the overall \$30 billion NIH budget. Spending for nursing research is a modest amount relative to the allocations for other health science institutes and for

major disease category funding. For NINR to adequately continue and further its mission, the institute must receive additional funding. Cuts in funding have impeded the institute from supporting larger comprehensive studies needed to advance nursing science and improve the quality of patient care. With increased appropriations for NINR, more comprehensive, complex, and longitudinal studies could be funded in the critical areas of their mission while maintaining their portfolio of current goals, projects, and priorities of the institute.

Additionally, considering that NINR presently allocates 6 percent of its budget to training that helps develop the pool of nurse researchers, increased funding would support NINR's efforts to prepare faculty researchers desperately needed to educate new nurses. AACN respectfully requests \$163 million for the National Institute of Nursing Research in fiscal year 2012.

NURSE-LED PRACTICE MODELS: INVESTING IN NURSE-MANAGED HEALTH CLINICS

The Affordable Care Act amended Sec. 330 of the Public Health Service Act, allowing Nurse-Managed Health Clinics (NMHCs) to apply for grant funds to help cover the costs of operating these unique community-based settings. NMHCs are nurse-practice arrangements and are managed by APRNs who provide primary care or wellness services to underserved or vulnerable populations through clinics located in places like public housing, churches, Native American reservations, rural communities, senior citizen centers, elementary schools, and storefronts. Each of these clinics is associated with a school, college, university or department of nursing, federally qualified health center, or independent nonprofit health or social services agency, and serves as safety net of providers for vulnerable populations. Moreover, NMHCs play a valuable role as teaching and practice sites for nursing students. AACN respectfully requests \$20 million for the Nurse-Managed Health Clinics authorized under Title III of the Public Health Service Act in fiscal year 2012 as recommended in the President's budget proposal.

CAPACITY GRANTS: SOLUTIONS TO GROW ENROLLMENT

According to AACN's latest enrollment and graduation survey, the major barriers to increasing student capacity in nursing schools are insufficient numbers of faculty, admission seats, clinical sites, classroom space, and clinical preceptors, as well as budget constraints. The Capacity for Nursing Students and Faculty Program, a section of the Higher Education Opportunity Act of 2008, offers capitation grants (formula grants based on the number of students enrolled/or matriculated) to nursing schools allowing them to increase the number of students. Schools of nursing continue to face budget cuts at the State level, and capacity grants are a proven method for meeting the needs of nursing education. AACN respectfully requests \$25 million for this program in fiscal year 2012.

CONCLUSION

AACN acknowledges the fiscal challenges facing this Subcommittee and Congress, but would be remiss in not highlighting the benefits of these programs. Title VIII has a long and successful record of providing dedicated support for the nursing workforce. The National Institute of Nursing Research invests in developing the scientific basis for quality nursing care. Nurse-Managed Health Clinics provide services to the underserved and training and practice settings for nursing students. The Capacity for Nursing Students and Faculty Program would allow schools to increase student capacity.

To be effective in meeting the critical goals outlined in the IOM's report, *The Future of Nursing: Leading Change, Advancing Health*, and the larger health reform goals of the Nation, these programs must receive additional funding. AACN respectfully requests \$313.075 million for Title VIII programs, \$163 million for NINR, \$20 million for Nurse-Managed Health Clinics, and \$25 million for the Capacity for Nursing Students and Faculty Program in fiscal year 2012. Additional funding for these programs will assist schools of nursing to expand their educational and research programs, educate more nurse faculty, increase the number of practicing RNs, and ultimately improve the patient care provided in our healthcare system.

PREPARED STATEMENT OF THE AMERICAN ASSOCIATION OF COLLEGES OF OSTEOPATHIC MEDICINE

On behalf of the American Association of Colleges of Osteopathic Medicine (AACOM), I am pleased to submit this testimony in support of increased funding in fiscal year 2012 for programs at the Health Resources Services Administration

(HRSA), the National Institutes of Health (NIH), and the Agency for Healthcare Research and Quality (AHRQ). AACOM represents the administrations, faculty, and students of the Nation's 26 colleges of osteopathic medicine at 34 locations in 26 States. Today, more than 19,000 students are enrolled in osteopathic medical schools. Nearly one in five U.S. medical students is training to be an osteopathic physician.

Title VII

The health professions education programs, authorized under Title VII of the Public Health Service Act and administered through HRSA, support the training and education of health practitioners to enhance the supply, diversity, and distribution of the healthcare workforce, acting as an essential part of the healthcare safety net and filling the gaps in the supply of health professionals not met by traditional market forces. Title VII and Title VIII nurse education programs are the only Federal programs designed to train clinicians in interdisciplinary settings to meet the needs of special and underserved populations, as well as increase minority representation in the healthcare workforce.

According to HRSA, an additional 33,000 health practitioners are needed to alleviate existing health professional shortages. Combined with faculty shortages across health professions disciplines, racial and ethnic disparities in healthcare, a growing, aging population and the anticipated demand for access to care, these needs strain an already fragile healthcare system. While AACOM appreciates the investments that have been made in these programs, we recommend increasing funding to \$449.4 million, the same funding level requested by the President, in fiscal year 2012 for the Title VII programs. Investment in these programs, including the Primary Care Training and Enhancement Program, the Health Careers Opportunity Program, and the Centers of Excellence, is necessary to address the primary care workforce shortage. Strengthening the workforce has been recognized as a national priority, and the investment in these programs recommended by AACOM will help meet the demand for a well-trained, diverse workforce that this country will witness as a result of healthcare reform.

Teaching Health Centers

The Teaching Health Center Graduate Medical Education Program (THCGME) is the first of its kind to shift graduate medical education (GME) training to community-based care settings that emphasize primary care and prevention. It is uniquely positioned to provide much needed primary care training in underserved populations. However, because the program is the first of its kind, most community-based settings do not have existing infrastructure to provide this training. AACOM strongly supports the President's budget request of \$10 million to fund the THC Development Grants. This funding would allow potential THC training sites to develop the infrastructure needed to administer residency training programs.

National Health Service Corps

Approximately 50 million Americans live in communities with a shortage of health professionals, lacking adequate access to primary care. Through scholarships and loan repayment, the National Health Service Corps (NHSC) supports the recruitment and retention of primary care clinicians to practice in underserved communities. At the close of fiscal year 2010, the NHSC provided a network of 7,500 primary healthcare professionals in 10,000 sites in underserved communities. However, this still fell approximately 20,000 practitioners short of fulfilling the need for primary care, dental and mental health practitioners in Health Professional Shortage Areas (HPSAs). Growth in HRSA's Community Health Center Program must be complemented with increases in the recruitment and retention of primary care clinicians to ensure adequate staffing, which the NHSC provides. AACOM supports the President's budget request of \$418 million for this program. This includes \$295 million from the Affordable Care Act (ACA) fund for the NHSC and \$24.695 million in appropriated dollars for field placements and \$98.7 million in appropriated dollars for recruitment.

National Institutes of Health

Research funded by the NIH leads to important medical discoveries regarding the causes, treatments, and cures for common and rare diseases, as well as disease prevention. These efforts improve our Nation's health and save lives. To maintain a robust research agenda, further investment will be needed. AACOM recommends \$32 billion in fiscal year 2012 for the NIH. While the need is significantly greater, approximately \$35.0 billion, anything less than the President's request will result in a reduction in real dollars dedicated to research.

With today's increasingly demanding and evolving medical curriculum, there is a critical need for more research geared toward evidence-based osteopathic medicine. AACOM believes that it is vitally important to maintain and increase funding for biomedical and clinical research in a variety of areas related to osteopathic principles and practice, including osteopathic manipulative medicine and comparative effectiveness. In this regard, AACOM supports the President's budget request of \$131.002 million for NIH's National Center for Complementary and Alternative Medicine to continue fulfilling this essential research role.

Agency for Healthcare Research and Quality

AHRQ supports research to improve healthcare quality, reduce costs, advance patient safety, decrease medical errors, and broaden access to essential services. AHRQ plays an important role in producing the evidence base needed to improve our Nation's health and healthcare. The incremental increases for AHRQ's Patient Centered Health Research Program in recent years, as well as the funding provided to AHRQ in the ARRA, will help AHRQ generate more of this research and expand the infrastructure needed to increase capacity to produce this evidence. More investment is needed, however, to fulfill AHRQ's mission and broader research agenda, especially research in patient safety and prevention and care management research. AACOM recommends \$405 million in fiscal year 2012 for AHRQ. This investment will preserve AHRQ's current programs while helping to restore its critical healthcare safety, quality, and efficiency initiatives.

AACOM is grateful for the opportunity to submit its views and looks forward to continuing to work with the Subcommittee on these important matters.

PREPARED STATEMENT OF THE AMERICAN ASSOCIATION OF COLLEGES OF PHARMACY

AACP and its member colleges and schools of pharmacy appreciate the continued support of the U.S. House of Representatives Appropriations Subcommittee on Labor, Health and Human Services, and Education. Our Nation's 124 accredited colleges and schools of pharmacy are engaged in a wide-range of programs supported by grants and funding administered through the agencies of the Department of Health and Human Services (HHS) and the Department of Education. We also understand the difficult task you face annually in your deliberations to do the most good for the Nation and remain fiscally responsible to the same. AACP respectfully offers the following recommendations for your consideration as you undertake your deliberations.

U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES SUPPORTED PROGRAMS AT
COLLEGES AND SCHOOLS OF PHARMACY

Agency for Healthcare Research and Quality (AHRQ)

AACP supports the Friends of AHRQ recommendation of \$405 million for AHRQ programs in fiscal year 2012.

Pharmacy faculty are strong partners with the Agency for Healthcare Research and Quality (AHRQ).

- Vincent J. Willey, Associate Professor at the University of the Sciences in Philadelphia, was appointed to the Comparative Effectiveness Research Pharmacy Workgroup.
- AHRQ Effective Healthcare programs including the Center for Education and Research on Therapeutics (CERTs) and the Developing Evidence to Inform Decisions about Effectiveness (DECIDE) support pharmacy faculty researchers focused on improving the effectiveness of healthcare services.
- Researcher faculty at The University of Arizona College of Pharmacy's Center for Health Outcomes and PharmacoEconomic Research, support the Arizona CERT and its mission to improve therapeutic outcomes and reduce adverse events caused by drug interactions and drugs that prolong the QT interval, especially those affecting women. Researchers determined that certain drug combinations increased the risk of death. Published research from this CERT includes the 2010 Women's Health Research: Progress, Pitfalls and Promise, for the Institute of Medicine and a comparison study on the U.S. Department of Veterans Affairs drug-drug interactions compared to two standard compendia.
#U18 HS17001
- Almut G. Winterstein, University of Florida, has received a 2-year \$482,000 award from the Agency for Healthcare Research and Quality for "Comparative Safety and Effectiveness of Stimulants in Medicaid Youth with ADHD."
#5R01HS018506-02

- Sean D. Sullivan, University of Washington, received a \$2.45 million grant from AHRQ to implement the multidisciplinary Mentored Clinical Scientist Comparative Effectiveness Research Career Development (K12) Program in collaboration with research partners at Group Health Research Institute, the Fred Hutchinson Cancer Research Center, and the Veterans' Administration Health Services Research and Development Center of Excellence. #1K12HS019482-01
- Daniel C. Malone, University of Arizona, received a 3-year grant from AHRQ for \$1.25 million, to evaluate awareness of CER guides by pharmacists and physicians and identify critical skills needed to use these reviews to support and encourage safe and effective prescribing of medications. #1R18HS019220-01

Centers for Disease Control and Prevention (CDC)

AACP supports the CDC Coalition recommendation of \$7.7 billion for CDC core programs in fiscal year 2012 and the Friends of NCHS recommendation of \$162 million for the National Center for Health Statistics.

The educational outcomes of a pharmacist's education include those related to public health. When in community-based positions, pharmacists are frequently providers of first contact. The opportunity to identify potential public health threats through regular interaction with patients provides public health agencies such as the CDC with on-the-ground epidemiologists. Pharmacy faculty are engaged in CDC-supported research in areas such as immunization delivery, integration of pharmacogenetics in the pharmacy curriculum and inclusion of pharmacists in emergency preparedness. Information from the National Center for Health Statistics (NCHS) is essential for faculty engaged in health services research and for the professional education of the pharmacist.

- Katie J. Suda, faculty member at the University of Tennessee, was supported by CDC funding to conduct a national analysis of outpatient anti-infective prescribing patterns. She also prepared a continuing education program in partnership with the CDC entitled, "Weighing in on Antibiotic Resistance: Community Pharmacists Tip the Scale," featured on the CDC Web site: <http://www.cdc.gov/getsmart/specific-groups/hcp/ce-course.html>. The program details the CDC's Get Smart program, focused on decreasing the amount of unnecessary antibiotics in the community.
- Grace Kuo, Associate Professor of Clinical Pharmacy at the University of California San Diego, founded PharmGenEd™, an evidence-based pharmacogenomics education program designed for pharmacists and physicians, pharmacy and medical students, and other healthcare professionals and is supported by funding from CDC. #IU38GD000070

Health Resources and Services Administration (HRSA)

AACP supports the Friends of HRSA recommendation of \$7.65 billion for fiscal year 2012.

HRSA is a Federal agency with a wide-range of policy and service components. Faculty at colleges and schools of pharmacy are integral to the success of many of these. Colleges and schools of pharmacy are the administrative units for interprofessional and community-based linkages programs including geriatric education centers and area health education centers. Pharmacy faculty research issues related to rural health delivery. Student pharmacists benefit from diversity program funding including Scholarships for Disadvantaged Students.

Office of Pharmacy Affairs

AACP recommends a program funding of \$5 million for fiscal year 2012 for the Office of Pharmacy Affairs.

AACP member institutions are actively engaged in Office of Pharmacy Affairs (OPA) efforts to improve the quality of care for patients in federally qualified health centers and entities eligible to participate in the 340B drug discount program. The success of the HRSA Patient Safety and Clinical Pharmacy Collaborative is a direct result of past OPA actions linking colleges and schools of pharmacy with federally qualified health centers. The result of these links has been the establishment of medical homes that improve health outcomes for underserved and disadvantaged patients through the integration of clinical pharmacy services.

Office of Telehealth Advancement

Technology is an important component for improving healthcare quality and maintaining or increasing access to care. Colleges and schools of pharmacy utilize technology to increase access to care, improve care quality and to increase the reach of education to student and practicing pharmacists.

- Keri H. Naglosky, Marcia M. Worley, Timothy P. Stratton and Randall D. Seifert University of Minnesota, received a \$63,000 grant for their study, "Pilot

Study to Determine the Effectiveness of Pharmacist Provided MTM Using Face-to-Face and TeleMTM in the Treatment of Long-Haul Drivers with Hypertension Department of Transportation Classifications Stage 1, 2 and 3.”

- Leigh Ann Ross and Sarah Fontenot, faculty at the University of Mississippi, work with The Delta Health Alliance on many projects including its HRSA telehealth grant and as members of the HRSA Patient Safety Collaborative, receiving the Clinical Pharmacy Services Improvement Award in 2010. Five Delta hospitals have telemedicine capabilities as a result of its funding and 86,083 individuals received medical or health education services during the 2009–2010 fiscal year. #H2AIT16626

Poison Control Centers

HRSA grant funding supports the management of 10 of the 57 poison control centers by pharmacy faculty.

- In 2010, the Maryland Poison Center, headed by Bruce Anderson, faculty at the University of Maryland, answered ~36,000 human exposure calls, ~2,000 animal exposures and ~25,000 requests for poison or drug information and over 70 percent of the human exposure calls were managed on site, avoiding treatment at a healthcare facility. This year, Paul Starr, also at the University of Maryland, was recognized for his 20 years as a certified specialist in poison information. #H4BHS15526

Bureau of Health Professions (BHP)

AACP supports the Health Professions and Nursing Education Coalition (HPNEC) recommendation of \$762.5 million for Title VII and VIII programs in fiscal year 2012.

AACP member institutions are active participants in BHP programs. Two colleges of pharmacy are current grantees in the Centers of Excellence program (Xavier University School of Pharmacy). This program focuses on increasing the number of underserved individuals attending health professions institutions. Colleges and schools of pharmacy are also part of Title VII interprofessional and community-based linkages programs including Geriatric Education Centers and Area Health Education Centers. These programs are essential for creating the educational approaches necessary for the Institute of Medicine’s recommendations of improving quality through team-based, patient-centered care and serve as valuable experiential education sites for student pharmacists.

- Gayle A. Hudgins, faculty at the University of Montana, was awarded an ARRA supplement of \$132,446 from HRSA, Bureau of Health Professions, for equipment to enhance training for health professionals.

Food and Drug Administration (FDA)

AACP recommends a funding level of \$3.7 billion for FDA programs in fiscal year 2012.

The FDA sees the colleges and schools of pharmacy as essential partners in assuring the public has access to a healthcare professional well versed in the science of safety. Pharmacy faculty partner with the FDA to improve the drug manufacturing process through the National Institute for Pharmaceutical Technology and Education (NIPTE) and increase the science-base for decisions regarding drug and device safety and effectiveness.

- Dianne M. Cappelletty, Associate Professor at The University of Toledo, was recently appointed to serve on the advisory committee to the Division of Anti-Infective and Ophthalmology Products.
- James E. Polli, University of Maryland, received \$1,099,990 from the FDA for “Pharmacokinetic Studies of Epileptic Drugs: Evaluation of Brand & Generic Antiepileptic Drug Products in Patients.”

National Institutes of Health (NIH)

AACP supports the Ad Hoc Group for Medical Research recommendation of \$35 billion for fiscal year 2012.

Pharmacy faculty are supported in their research by nearly every institute at the NIH. The NIH-supported research at AACP member institutions spans the research spectrum from the creation of new knowledge through the translation of that new knowledge to providers and patients. In 2010, pharmacy faculty researchers received more than \$358 million in grant support from the NIH. AACP member institutions are concerned, as are other health professions education organizations, of the need to increase the number of biomedical researchers.

- At the University of California, San Francisco, Kathleen M. Giacomini and co-lead Deanna L. Kroetz received \$15.1 million in funding over the next 5 years from the NIH for research into the genetics behind membrane transporters and

- a branch project from that research that will focus on the genetic factors that determine responses to the anti-diabetic drug, metformin in African American patients with type 2 diabetes. #2U19GM061390-11
- Alice M. Clark and Ameeta K. Agarwal, University of Mississippi, received \$388,221 from the National Institute of Allergy and Infectious Diseases to study New Drugs for Opportunistic Infections. #5R01AI027094-21
- Eugene D. Morse, the University at Buffalo, received two grants: \$952,000 in funding for, “Clinical Pharmacology Quality Assurance and Quality Control” funded by the National Institute of Allergies and Infectious Diseases/Division of AIDS and \$2.3 Million for, “Clinical Pharmacology Lab from NIH to Promote HIV Research in Africa.” #272200800019C-4-0-1
- Jordan K. Zjawiony and Charles L. Burandt, the University of North Carolina, received \$71,500 from the NIH to study Chemistry and Pharmacology of Newly Emerging Psychoactive Plants-Year 2. #5R03DA023491-02

U.S. DEPARTMENT OF EDUCATION SUPPORTED PROGRAMS AT COLLEGES AND SCHOOLS
OF PHARMACY

AACP supports the Student Aid Alliance’s recommendations for:

- Pell Grant maximum be maintained at \$5,550;
- Gaining Early Awareness and Readiness for Undergraduate Programs (GEAR UP) should be funded at \$333 million; and
- Maintaining the in-school interest subsidy for graduate program loans.

AACP recommends a funding level of \$160 million for the Fund for the Improvement of Post Secondary Education (FIPSE).

The Department of Education supports the education of healthcare professionals by:

- assuring access to education through student financial aid programs;
- supporting educational research allows faculty to determine improvements in educational approaches; and
- maintaining the oversight of higher education through the approval of accrediting agencies.

AACP actively supports increased funding for undergraduate student financial assistance programs. Admission to into the pharmacy professional degree program requires at least 2 years of undergraduate preparation. Student financial assistance programs are essential to assuring colleges and schools of pharmacy are accessible to qualified students. Likewise, financial assistance programs that support graduate education are an important component meeting our Nation’s need for scientists and educators.

PREPARED STATEMENT OF THE AMERICAN ASSOCIATION OF IMMUNOLOGISTS

The American Association of Immunologists (AAI), a not-for-profit professional association representing more than 7,000 of the world’s leading experts on the immune system, appreciates having this opportunity to submit testimony regarding fiscal year 2012 appropriations for the National Institutes of Health (NIH). The vast majority of AAI members, whose crucially important discoveries help to prevent, treat and cure disease, depends on NIH funding to support their work.¹

For more than 50 years, NIH has been envy of the world and has been instrumental in promoting science, better health, and discovery. Unlike many Federal agencies, NIH distributes most of its funding to scientists working in all 50 States. In fact, about 80 percent of the \$31.2 billion NIH budget is awarded to scientists working at research institutions throughout the United States, making NIH funding the foundation of our Nation’s biomedical research infrastructure and a key factor in local and national economic growth.² In addition to its positive economic impact on a community, NIH funding supports highly skilled jobs that focus on improving

¹AAI members work in academia, government, and industry. Many members receive grants from the National Institute of Allergy and Infectious Diseases, the National Cancer Institute, the National Institute on Aging, and the National Institute of Arthritis and Musculoskeletal and Skin Diseases, as well as other NIH Institutes and Centers.

²NIH funding supports “almost 50,000 competitive grants to more than 325,000 researchers at over 3,000 universities, medical schools, and other research institutions in every State and around the world.” See <http://www.nih.gov/about/budget.htm> (3/9/11). According to NIH Director Francis Collins M.D., Ph.D., “every dollar that NIH gives out in a grant returns over \$2 in investments in terms of economic goods and services that are produced within just 1 year.” “Francis S. Collins,” April 26, 2010, <http://pubs.acs.org/cen/coverstory/88/8817cover.html>.

human health.³ NIH funding also helps train the next generation of inventors and innovators, crucial to the nation's future job creation and pipeline of new therapeutics.

The role of the immune system

The immune system's job is to protect its human or animal host from a wide range of infectious and chronic diseases. When the immune system works, the host remains healthy. But many infectious diseases, including influenza, HIV/AIDS, malaria, tuberculosis, salmonella, and the common cold, challenge and sometimes overcome the defenses mounted by the immune system. And many chronic diseases, including cancer, diabetes, multiple sclerosis, rheumatoid arthritis, asthma, inflammatory bowel disease, and lupus, are either caused by—or due in large part to—an overactive (autoimmune) or underactive immune response.⁴ Advances in immunological research have already yielded progress in preventing, diagnosing, and treating some of these diseases, but further progress depends on increased knowledge in the field of immunology.

A young and evolving discipline,⁵ immunology has already answered many key questions and is now needed to explore urgent new challenges to community and global health, including understanding the human and animal immune response to: (1) pathogens that threaten to become the next pandemic, (2) man-made and natural infectious organisms that are potential agents of bioterrorism (including plague, smallpox, and anthrax),⁶ (3) environmental threats, and (4) cancer. While researchers and public health professionals must respond quickly to these emergent threats, AAI believes that the best preparation is to support consistent, ongoing research rather than to “ramp up” research in times of emergency.⁷

Recent advances in immunological research

Immunological research has led to unprecedented medical advances in recent years, including new treatments for lupus and malignant melanoma, and new vaccines against influenza and cervical cancer.

The value of vaccination against disease and the importance of continued research and evaluation cannot be overstated. Recent expansion of the influenza vaccine to all U.S. children “may induce herd immunity against influenza for older adults and has the potential to be more beneficial to older adults than the existing policy of preventing influenza by vaccinating older adults themselves.”⁸ A recent study has shown the efficacy of vaccinating older adults, whether healthy or with chronic diseases, against shingles, a painful blistering skin rash caused by the varicella-zoster virus, the virus that causes chickenpox.⁹ Most recently, a new vaccine against rotavirus has greatly reduced hospital admissions in the United States in babies with infectious diarrhea and markedly decreased deaths in infants in the developing

³ “[E]very grant that NIH gives creates seven high-quality, high-paying jobs that sustain American leadership in science.” “Francis S. Collins,” April 26, 2010, <http://pubs.acs.org/cen/coverstory/88/8817cover.html>.

⁴ The immune system works by recognizing and attacking bacteria and viruses inside the body and by controlling the growth of tumor cells. A healthy immune system can protect its human or animal host from illness or disease either entirely—by destroying the virus, bacterium, or tumor cell—or partially, resulting in a less serious illness. It is also responsible for the rejection response following transplantation of organs or bone marrow. The immune system can also malfunction, causing the body to attack itself, resulting in an “autoimmune” disease, such as Type 1 diabetes, multiple sclerosis, lupus or rheumatoid arthritis.

⁵ Although the first vaccine (against smallpox) was developed in 1798, most of our basic understanding of the immune system has developed in the last 50 years, and the pace of discovery is rapidly increasing.

⁶ To best protect against bioterrorism, scientists should focus on basic research, including working to understand the immune response, identifying new and potentially modified pathogens, and developing tools (including new and more potent vaccines) to protect against these pathogens.

⁷ For example, to best protect against a pandemic, scientists should focus on basic research to combat seasonal flu, including building capacity, pursuing new production methods, and seeking optimized flu vaccines and delivery methods.

⁸ Cohen SA, Chui K, Naumova E, “Influenza Vaccination in Young Children Reduces Influenza-associated Hospitalizations in Older Adults, 2002–2006,” *Journal of the American Geriatrics Society*, 2011; 59(2):327–332.

⁹ Tseng HF, Smith N, Harpaz R, Bialek SR, Sy LS, Jacobsen SJ, “Herpes zoster vaccine in older adults and the risk of subsequent herpes zoster disease,” *Journal of the American Medical Association*, 2011 Jan 12; 305(2):160–166.

world.¹⁰ Thousands of children will not die due to the results of immunological and infectious disease research originally funded by the NIH on this killer virus.

Recently, immunologists have advanced the understanding of the exquisitely precise regulation of the immune system and are very hopeful that this understanding will allow for therapeutic manipulation of the immune system. This important discovery about immune-system regulation could lead to new approaches for the prevention and treatment of numerous autoimmune diseases, including lupus (systemic lupus erythematosus),¹¹ a serious chronic autoimmune disease affecting about 1.5 million Americans. Finally, new monoclonal antibodies (highly specific immune molecules) that block the immune response of people with autoimmune diseases (in which one's immune system attacks one's own body) show enormous promise in improving these debilitating diseases.

Sustaining NIH Funding in a Difficult Fiscal Climate

AAI greatly appreciates the strong historical support of this subcommittee for biomedical research, from doubling the NIH budget (fiscal year 1999 to fiscal year 2003), to passing the Appropriations Acts for fiscal year 2009 and 2010, to including in the American Recovery and Reinvestment Act of 2009 ("ARRA") a \$10.4 billion supplemental appropriation for NIH. As a result of this generous support, NIH has been able to fund many excellent, innovative projects with great promise for advancing human health, and to invest in the Nation's research infrastructure. AAI—and the entire biomedical research community—are deeply grateful for this support and for the subcommittee's strong bipartisan commitment to advancing medical research. And yet, AAI comes to you this year deeply concerned about efforts to cut, rather than invest in, the NIH budget. Imminent advances may not come to fruition if the fiscal year 2012 appropriations level is unable to support NIH's current functional capacity (~\$34.4 billion), made possible in large part by this subcommittee's prior support. AAI remains concerned that investment in biomedical research continues unfettered by our global competitors, while our challenged budget makes it difficult for us to attract the best and brightest to these crucial scientific fields. The AAI funding recommendation for fiscal year 2012 is premised on these concerns.

NIH Funding for Fiscal Year 2012

AAI greatly appreciates the President's proposed increase for NIH for fiscal year 2012 (\$31.98 billion, or 4 percent increase over the regular fiscal year 2011 appropriations level). More is required, however, for NIH to be able to support existing research projects and fund a reasonable number of excellent new ones. AAI therefore urges the subcommittee to provide NIH with a fiscal year 2012 budget of \$35 billion to enable NIH to maintain its current functional capacity and to provide a small funding boost for important new research. Sustained funding, particularly in this challenging fiscal climate, would not only stabilize ongoing research projects and the overall research enterprise, but also inspire confidence in the system among many of our brightest young students who are considering (but due to such limited grant funding, are fearful to begin) careers in biomedical research.

NIH priorities for Fiscal Year 2012

AAI believes strongly that the engine for biomedical innovation and discovery is individual investigator-initiated research. Researchers working in laboratories around the country, with their scientific collaborators around the world, are the best source of scientific advancement and progress. "Top-down" science, where Government directives force the research in specified directions, is less likely to achieve the desired goals than funding the best, most promising, ripest grant applications.

AAI strongly supports the President's request for a \$436 million increase in funding for individual research project grants (RPGs) that fund individual scientists. Unfortunately, this increase will only support approximately 43 additional RPGs. AAI notes that the President's budget includes \$100 million to establish the Cures Acceleration Network (CAN). AAI recommends a significantly smaller appropriation for the first year of this program, with the remainder going to support additional RPGs.

¹⁰Esposito DH, Tate JE, Kang G, Parashar UD. "Projected impact and cost-effectiveness of a rotavirus vaccination program in India, 2008," *Clinical Infectious Diseases*, 2011; 52 (2):171–177. Gagneur A, Nowak E, Lemaitre T, Segura JF, Delaperrière N, Abalea L, Poulhazan E, Jossens A, Auzanneau L, Tran A, Payan C, Jay N, de Parscau L, Oger E, "Impact of rotavirus vaccination on hospitalizations for rotavirus diarrhea: The IVANHOE study," *Vaccine*, 2011 March 25, doi:10.1016/j.vaccine.2011.03.035.

¹¹Kim HJ, Verbinen B, Tang X, Linrong L, Cantor H, "Inhibition of follicular T-helper cells by CD8+ regulatory T cells is essential for self tolerance," *Nature*, 2010 July 22; 467: 328–322.

AAI supports the President's request for \$300 million for the Global Fund to Fight AIDS, Tuberculosis, and Malaria—infectious diseases which devastate people and communities around the world.

AAI supports the President's proposed 4 percent increase for the National Research Service Awards, a long-needed training stipend increase for young scientists who are the next generation of research leaders.

AAI urges this subcommittee to do all it can to reduce the time-consuming, distracting, and unnecessary administrative burden that too often accompanies the receipt of Government funds.

AAI recommends strongly against any legislative effort to determine the size and number of NIH grants. Such a decision should be a scientific one made by NIH.

AAI supports the President's request for \$1.538 billion for NIH Research, Management, and Services (RM&S) to fund the management, monitoring, and oversight of all research activities. Only through adequate funding of this account will NIH be able to supervise and oversee its large and complex portfolio.

The NIH Public Access Policy

AAI requests that the subcommittee require NIH to publicly report on the current and historical cost of the NIH Public Access Policy ("Policy"), and receive the response of private scientific publishers to this information. AAI continues to believe that the Policy duplicates publications and services which are already provided cost-effectively and well by the private sector, including not-for-profit scientific societies. AAI and other private sector publishers already publish—and make publicly available—thousands of scientific journals with millions of articles that report cutting-edge research funded by NIH and other entities. AAI urges that the subcommittee require NIH to partner with, rather than compete with, private publishers to enhance public access while addressing publishers' key concerns, including respecting copyright law and ensuring journals' continued ability to provide quality, independent peer review of NIH-funded research.

Conclusion

AAI thanks the subcommittee for its strong support for biomedical research, the NIH, and the biomedical researchers who devote their lives to scientific discovery and the prevention, treatment, and cure of disease.

PREPARED STATEMENT OF THE AMERICAN ASSOCIATION OF NURSE ANESTHETISTS

FISCAL YEAR 2012 APPROPRIATIONS REQUEST SUMMARY

	Fiscal year—			AANA fiscal year 2012 request
	2010 actual	2011 budget	2012 budget	
HHS/HRSA/BHPr Title VIII Advanced Education Nursing, Nurse Anesthetist Education Reserve	¹ \$3,500,000	(²)	(²)	³ \$4,000,000
Total for Advanced Education Nursing, from Title VIII	64,440,000	64,440,000	104,438,000	104,438,000
Title VIII HRSA BHPr Nursing Education Programs	243,872,000	243,872,000	313,075,000	313,075,000
CDC/Division of Healthcare Quality and Promotion			(⁴)	(⁴)

¹ Awards amounted to approximately.

² Grant allocations not specified.

³ For nurse anesthesia education.

⁴ Maintain level funding.

The American Association of Nurse Anesthetists (AANA) is the professional association for the 44,000 Certified Registered Nurse Anesthetists (CRNAs) and student nurse anesthetists practicing today, representing over 90 percent of the nurse anesthetists in the United States. Today, CRNAs deliver approximately 32 million anesthetics to patients each year in the United States. CRNA services include administering the anesthetic, monitoring the patient's vital signs, staying with the patient throughout the surgery, and providing acute and chronic pain management services. CRNAs provide anesthesia for a wide variety of surgical cases and in some States are the sole anesthesia providers in 100 percent of rural hospitals, affording these medical facilities obstetrical, surgical, and trauma stabilization, and pain management capabilities. CRNAs work in every setting in which anesthesia is delivered, including hospital surgical suites and obstetrical delivery rooms, ambulatory surgical centers (ASCs), pain management units and the offices of dentists, podiatrists and plastic surgeons. Nurse anesthetists are experienced and highly trained anesthesia professionals whose record of patient safety in the field of anesthesia was bolstered by the Institute of Medicine report in 2000, which found that anesthesia is

50 times safer than in the 1980s. (Kohn L, Corrigan J, Donaldson M, ed. *To Err is Human*. Institute of Medicine, National Academy Press, Washington DC, 2000.) Nurse anesthetists continue to set for themselves the most rigorous continuing education and re-certification requirements in the field of anesthesia. Relative anesthesia patient safety outcomes are comparable among nurse anesthetists and anesthesiologists, with a recent Health Affairs article, “No Harm Found When Nurse Anesthetists Work without Supervision by Physicians” finding that adverse outcomes were no more prevalent in States that opted out of the Medicare physician supervision requirement of nurse anesthetists than those States that didn’t opt-out (Dulisse B, Cromwell J. No Harm Found When Nurse Anesthetists Work Without Supervision By Physicians. *Health Aff.* 2010;29(8):1469–1475).

In addition, a study published in *Nursing Research* indicates that obstetrical anesthesia, whether provided by CRNAs or anesthesiologists, is extremely safe, and there is no difference in safety between hospitals that use only CRNAs compared with those that use only anesthesiologists. (Simonson, Daniel C et al. *Anesthesia Staffing and Anesthetic Complications During Cesarean Delivery: A Retrospective Analysis*. *Nursing Research*, Vol. 56, No. 1, pp. 9–17. January/February 2007). In addition, a recent AANA workforce study showed that CRNAs and anesthesiologists are substitutes in the production of surgeries. Through continual improvements in research, education, and practice, nurse anesthetists are vigilant in our efforts to ensure patient safety.

CRNAs provide the lion’s share of anesthesia care required by our U.S. Armed Forces through active duty and the reserves. For decades, CRNAs have staffed ships, remote U.S. military bases, and forward surgical teams without physician anesthesiologist support. In addition, CRNAs predominate in rural and medically underserved areas, and where more Medicare patients live.

Importance of Title VIII Nurse Anesthesia Education Funding

The nurse anesthesia profession’s chief request of the Subcommittee is for \$4 million to be reserved for nurse anesthesia education and \$104.438 million for advanced education nursing from the Title VIII program. We feel that this funding request is well justified, as we know that more baby boomers retiring will not only reduce our nurse workforce from retirements but will increase the demand from an aging population requiring care. The Title VIII program is an effective means to help address the nurse anesthesia workforce demand.

Increasing funding for advanced education nursing from \$64.44 million in fiscal year 2010 to \$104.438 million is necessary to meet the continuing demand for nursing faculty and other advanced education nursing services throughout the United States. The program provides for competitive grants that help enhance advanced nursing education and practice and traineeships for individuals in advanced nursing education programs. This funding is critical to meet the nursing workforce needs of Americans who require healthcare, particularly as we see more patients enter the system with health reform. More APRNs will be needed to fill the gap to ensure access to care. In addition, this funding provides a two-fold benefit for the nurse workforce. It not only seeks to increase the number of providers in rural and underserved America but also prepares providers at the master’s and doctoral levels, increasing the number of clinicians who are eligible to serve as faculty.

There continues to be high demand for CRNA workforce in clinical and educational settings. The supply of clinical providers has increased in recent years, stimulated by increases in the number of CRNAs trained. Between 2000–2009, the number of nurse anesthesia educational program graduates doubled, with the Council on Certification of Nurse Anesthetists (CCNA) reporting 1,075 graduates in 2000 and 2,375 graduates in 2010. This growth is leveling off somewhat, but is expected to continue. However, even though the number of graduates has doubled in 8 years, the demand for nurse anesthetists continues to rise as the population ages, the number of clinical sites requiring anesthesia services grows, and CRNA retirements increase.

The problem is not that our 111 accredited programs of nurse anesthesia are failing to attract qualified applicants. It is that they have to turn them away by the hundreds. The capacity of nurse anesthesia educational programs to educate qualified applicants is limited by the number of faculty, the number and characteristics of clinical practice educational sites, and other factors. A qualified applicant to a CRNA program is a bachelor’s educated registered nurse who has spent at least 1 year serving in an acute care healthcare practice environment.

Recognizing the important role nurse anesthetists play in providing quality healthcare, the AANA has been working with the 111 accredited nurse anesthesia educational programs to increase the number of qualified graduates. In addition, the AANA has worked with nursing and allied health deans to develop new CRNA pro-

grams. To truly meet the nurse anesthesia workforce challenge, the capacity and number of CRNA schools must continue to grow. With the help of competitively awarded grants supported by Title VIII funding, the nurse anesthesia profession is making significant progress, expanding both the number of clinical practice sites and the number of graduates.

The AANA is pleased to report that this progress is extremely cost-effective from the standpoint of Federal funding. Anesthesia can be provided by nurse anesthetists, physician anesthesiologists, or by CRNAs and anesthesiologists working together. As mentioned earlier, the Health Affairs study by Dulisse and Cromwell indicates the safety of CRNA care. Another study published recently in *Nursing Economic\$* indicates that costs of educating and training a CRNA from undergraduate education through graduate education is roughly 15 percent of the cost of educating and training an anesthesiologist (Hogan, PF, Seifert RF, Moore CS, Simonson BE, Cost Effectiveness Analysis of Anesthesia Providers, *Nurs Econ.* 2010;28(3): 150–169.) This study also found that among anesthesia delivery models, CRNAs acting independently provide anesthesia services at the lowest economic cost; costs for this model are 25 percent less than the second lowest cost model in which an anesthesiologist supervises six CRNAs. Nurse anesthesia education represents a significant educational cost-benefit for supporting CRNA educational programs with Federal dollars vs. supporting other, more costly, models of anesthesia education.

To further demonstrate the effectiveness of the Title VIII investment in nurse anesthesia education, the AANA surveyed its CRNA program directors to gauge the impact of the Title VIII funding. Of the eleven schools that had reported receiving competitive Title VIII Nurse Education and Practice Grants funding from 1998 to 2003, the programs indicated an average increase of at least 15 CRNAs graduated per year. They also reported on average more than doubling their number of graduates. Moreover, they reported producing additional CRNAs that went to serve in rural or medically underserved areas.

We believe the Subcommittee should allocate \$4 million for nurse anesthesia education for several reasons. First, as this testimony has documented, the funding is cost-effective and needed. Second, this particular funding meets a distinct need not met elsewhere; nurse anesthesia for rural and medically underserved America is not affected by increases in the budget for the National Health Service Corps and community health centers, since those initiatives are for delivering primary and not surgical healthcare. Third, this funding meets an overall objective to increase access to quality healthcare in medically underserved America.

Title VIII Funding for Strengthening the Nursing Workforce

The AANA joins The Nursing Community and the Americans for Nursing Shortage Relief (ANSR) Alliance in support of the Subcommittee providing a total of \$313.075 million in fiscal year 2012 for nursing shortage relief through Title VIII. AANA asks that of the \$313.075 million, \$104.438 million go to Advanced Education Nursing and \$4 million go to nurse anesthesia education to help increase clinicians in underserved communities and those eligible to serve as faculty. The AANA appreciates the support for nurse education funding in fiscal year 2010 and past fiscal years from this Subcommittee and from the Congress.

In the interest of patients past and present, particularly those in rural and medically underserved parts of this country, we ask Congress to invest in CRNA and nursing educational funding programs and to provide these programs the sustained increases required to help ensure Americans get the healthcare that they need and deserve. Quality anesthesia care provided by CRNAs saves lives, promotes quality of life, and makes fiscal sense. This Federal support for Title VIII and advanced education nurses will improve patient access to quality services and strengthen the Nation's healthcare delivery system.

Safe Injection Practices

As a leader in patient safety, the AANA has been playing a vigorous role in the development and projects of the Safe Injection Practices Coalition, intended to reduce and eventually eliminate the incidence of healthcare facility acquired infections. Provider education and awareness, detection, tracking and response are all extremely important to preventing healthcare-associated infections. In the interest of promoting safe injection practice and reducing the incidence of healthcare facility acquired infections, we recommend the Committee maintain its level of funding for CDC's Division of Healthcare Quality and Promotion so they can address outbreaks and promote innovative ways to adhere to injection safety and infection control guidelines. We also hope the committee will support the CDC's efforts around provider education and patient awareness activities, as this issue transcends provider

type and it's important to educate all types of providers and patients alike. In light of the recent healthcare-associated transmission of blood-borne pathogens in California, North Carolina, Florida, Colorado, and Nevada, the CDC needs resources to use the knowledge they have gained on detection and be able to develop new strategies to prevent healthcare associated transmission of blood borne pathogens.

PREPARED STATEMENT OF THE AMERICAN CONGRESS OF OBSTETRICIANS AND GYNECOLOGISTS

The American Congress of Obstetricians and Gynecologists, representing 54,000 physicians and partners in women's healthcare, is pleased to offer this statement to the Senate Committee on Appropriations, Subcommittee on Labor, Health and Human Services, and Education. We thank Chairman Harkin, and the entire Subcommittee for the opportunity to provide comments on important programs to women's health. Today, the United States lags behind other nations in healthy births, yet remains high in birth costs. ACOG's Making Obstetrics and Maternity Safer (MOMS) Initiative seeks to improve maternal outcomes through more research and better data, and we urge you to make this a top priority in fiscal year 2012.

Research is critically needed to understand why our maternal and infant mortality rate remains comparatively high. Having better data collection methods and comprehensive maternal mortality reviews has shown maternal mortality rates in some States, such as California, to be higher than previously thought. States without these resources are likely underreporting maternal and infant deaths and complications from childbirth. Without accurate data, the full range of causes of these deaths remains unknown. Effective research based on comprehensive data is a key MOMS element to developing and implementing evidence-based interventions.

The President's budget for fiscal year 2012 takes a positive first step toward this goal, including a \$1 billion increase for NIH, and ACOG requests the Subcommittee build on these increases to sustain the investment for women's health. Please note that given the current fiscal climate, our requests are more conservative this year and do not reflect the actual need in the health community. ACOG asks for a 1.7 percent increase over fiscal year 2010 to the NICHD within NIH to \$1.352 billion, a 2.3 percent increase for HRSA to \$7.65 billion, a 19 percent increase for CDC to \$7.7 billion, and a 2 percent increase for AHRQ to \$405 million.

Funding of research and programs in the following areas are vital to the MOMS Initiative:

Maternal Mortality Reviews at HHS

National data on maternal mortality is inconsistent and incomplete due to the lack of standardized reporting definitions and mechanisms. To capture the accurate number of maternal deaths and plan effective interventions, maternal mortality should be addressed through multiple, complementary strategies. ACOG recommends that HHS fund States in implementing maternal mortality reviews that would allow them to conduct regular reviews of all deaths within the State to identify causes, factors in the communities, and strategies to address the issues. Combined with adoption of the recommended birth and death certificates in all States and territories, CDC could then collect uniform data to calculate an accurate national maternal mortality rate. Results of maternal mortality reviews will inform research needed to identify evidence based interventions addressing causes and factors of maternal mortality and morbidity.

ACOG urges Congress to provide \$10 million to Health and Human Services to assist States in setting up maternal mortality reviews. ACOG also urges Congress to provide \$50,000 to NIH to hold a workshop to identify definitions for severe maternal morbidity and \$100,000 to HHS to develop a research plan to identify and monitor severe maternal morbidity.

Maternal/Child Health Research at the NIH

The Eunice Kennedy Shriver National Institute of Child Health and Human Development (NICHD) conducts the majority of women's health research. Despite the NIH's critical advancements, reduced funding levels have made it difficult for research to continue.

ACOG supports a 1.7 percent increase in funds over fiscal year 2010 to \$1.352 billion for the NICHD. A modest increase, these funds will assist the following research areas critical to the MOMS Initiative:

Reducing the Prevalence of Premature Births.—There is a known link between pre-term birth and infant mortality, and women of color are at increased risk for delivering pre-term. NICHD is helping our Nation understand how adverse conditions and health disparities increase the risks of premature birth in high-risk racial

groups, and how to reduce these risks. Prematurity rates have increased almost 35 percent since 1981, accounting for 12.5 percent of all births, yet the causes are unknown in 25 percent of cases. Preterm births cost the Nation \$26 billion annually, \$51,600 for every infant born prematurely. Direct healthcare costs to employers for a premature baby average \$41,610, 15 times higher than the \$2,830 for a healthy, full-term delivery.

Additional research is critically needed to understand how we can drive down our prematurity rates and NICHD conducts the majority of this research. For example, a 2003 NICHD study showed that progesterone supplementation reduces preterm birth in a select group of women, paving the way for its widespread clinical use. Today, around 139,000 (3.3 percent) women are candidates for this therapy. Among these women, 22 percent, or about 30,500, are likely to have a recurrent preterm birth without this treatment. With treatment, about one-third, or 10,000, of these preterm births can be prevented. The prevention of all 10,000 preterm births would result in direct medical cost savings of \$334 million and total medical cost savings of \$519 million. However, further studies are needed to determine if progesterone therapy can be designed to help prevent preterm delivery in other ways, including optimal preparation, dosage, and route of administration. The high cost of prematurity and past successful research at NICH highlights the need to sustain investments to reduce the rate of prematurity.

ACOG supports the Surgeon General's effort to make the prevention of pre-term birth a national public health priority, and urges Congress to allocate \$1 million to NICHD to create a Trans-disciplinary Research Center on Prematurity to help streamline efforts to reduce pre-term births.

Obesity Research, Treatment and Prevention.—Obese pregnant women are at higher risk for poor maternal and neonatal outcomes. Additional research and interventions are needed to address the increased risk for poor outcomes in obese women receiving infertility treatment, the increased incidence of birth defects and stillbirths in obese pregnant women, ways to optimize outcomes in obese women who become pregnant after bariatric surgery, and the increased future risk of childhood obesity in their offspring.

ACOG is grateful to the NIH for making obesity a priority and initiating trans-disciplinary approaches to combat obesity. The recent release of the Strategic Plan for NIH Obesity Research offers some innovative and promising directions for obesity research, and sustained funding is critical to implement the plan.

Training Programs.—The average investigator is in his/her forties before receiving their first NIH grant, a huge disincentive for students considering bio-medical research as a career. Complicating matters, there is a gap between the number of women's reproductive health researchers being trained and the need for such research. The NICHD-coordinated Women's Reproductive Health Research (WRHR) Career Development program seeks to increase the number of ob-gyns conducting scientific research in women's health in order to address this gap. To date 170 WRHR Scholars have received faculty positions, and 7 new and competing WRHR sites were added in 2010.

Additional funding to add new sites can help sustain this low-dollar, large impact training program while at the same time shoring up the women's reproductive research workforce.

Maternal/Child Health Programs at CDC

CDC funds programs that are critical to providing resources to mothers and children in need. Where NIH conducts research to identify causes of pre-term birth, CDC funds programs that provide resources to mothers to help prevent pre-term birth, and help identify factors contributing to pre-term birth and poor maternal outcomes.

ACOG supports a 19 percent increase in funds over fiscal year 2010 to \$7.7 billion to increase CDC's ability to bring prevention, treatment and interventions to more women and children in need, and to help enact some of the important provisions within healthcare reform. This funding will help the following programs important to the MOMS Initiative:

Electronic Birth Records and Death Records, National Center for Health Statistics (NCHS), National Vital Statistics System (NVSS).—NCHS is the Nation's principal health statistics agency; it collects, analyzes and reports on data critical to all aspects of our healthcare system. NCHS collects State data needed to monitor maternal and infant health, such as use of prenatal care, and smoking during pregnancy. This data allows investigators to monitor maternal and child health objectives, and develop efficient prevention and treatment strategies.

Uniform consistent data from birth and death records is critical to conducting research and directing public programs to combat maternal and infant death. Only 75

percent of States and territories use the 2003 recommended birth certificates and 65 percent have adopted the 2003 recommended death certificate. The President recently issued a Memorandum to all departments and agencies encouraging expanded data collection on maternal mortality by using the 2003 U.S. standard birth certificate and updating to electronic systems, noting that until all States adopt the same data standards it will be difficult to formulate national maternal mortality ratios.

ACOG urges Congress to allocate \$11 million for States to modernize their birth and death records systems to the 2003 recommended guidelines. It is a low cost that will yield enormous gains in CDC's ability to collect accurate data nationally and better direct medical research and best practice for physicians.

Safe Motherhood/Infant Health.—Two to three women a day die from delivery complications. The Safe Motherhood Program supports CDC's work to identify and gather information on pregnancy-related deaths; collect and provide information about women's health and health behaviors around pregnancy; and expand the use of guidelines on preconception care into everyday practice and healthcare policy.

Safe Motherhood also tracks infant morbidity and mortality associated with pre-term birth. ACOG is concerned with recent trends particularly among rates of late pre-term births. Increased funding is needed for CDC to improve national data systems to track pre-term birth rates and expand epidemiological research that focuses especially on the causes and prevention of preterm birth and births at 37–38 weeks gestation.

ACOG urges Congress to include a 23.7 percent increase in funds to \$55.4 million for Safe Motherhood, consistent with the President's fiscal year 2011 budget.

Maternal/Child Health Programs at HRSA

HRSA delivers critical resources to communities to improve the health of mothers and children. ACOG urges a 2.3 percent increase in funds over fiscal year 2010 to \$7.65 billion to increase the scope of HRSA programs, ultimately bringing more resources to more mothers and children. This funding will help expand the following programs important to the MOMS Initiative:

Fetal Infant Mortality Reviews, Healthy Start Program.—The U.S. infant mortality rate is again on the rise and is particularly severe among minority and low-income women. The infant mortality rate among African-American women has been increasing since 2001 and reached 14.2 deaths per 1,000 births in 2004. There also has been a startling rise in infant mortality in the South in the past few years.

The Healthy Start Program through HRSA promotes community-based programs that focus on infant mortality and racial disparities in perinatal outcomes. These programs are encouraged to use the Fetal and Infant Mortality Review (FIMR) which brings together ob-gyn experts and local health departments to help solve problems related to infant mortality. Today more than 220 local programs in 42 States find FIMR a powerful tool to help solve infant mortality.

ACOG urges Congress to include \$.5 million for Healthy Start Programs to include FIMR.

Maternal Child Health Block Grant (MCH)

The MCH is the only Federal program that exclusively focuses on improving the health of mothers and children. State and territorial health agencies and their partners use MCH Block Grant funds to reduce infant mortality, deliver services to children and youth with special healthcare needs, support comprehensive prenatal and postnatal care, screen newborns for genetic and hereditary health conditions, deliver childhood immunizations, and prevent childhood injuries.

These early healthcare services help keep women and children healthy, eliminating the need for later costly care. For example, every \$1 spent on preconception care programs for women with diabetes can reduce health costs by up to \$5.19 by preventing costly complications in both mothers and babies. Studies also suggest that every \$1 spent on smoking cessation counseling for pregnant women saves \$3 in neonatal intensive care costs.

ACOG urges Congress to increase funding for MCH \$700 million, a 5.74 percent increase over fiscal year 2010.

Title X Family Planning

The Title X program provides contraceptive services, immunizations and other preventive healthcare, including screenings for STDs, HIV, breast cancer, cervical cancer, high blood pressure, and anemia to more than 5 million low-income men and women at more than 4,500 service delivery sites. These programs improve maternal and child health outcomes, prevent unintended pregnancies, and reduce the rate of abortions. Every \$1 spent on family planning results in a \$4 savings to Medicaid.

Services provided at Title X clinics accounted for \$3.4 billion in healthcare savings in 2008 alone.

ACOG supports a 3.15 percent increase in funds for Title X to \$327 million, consistent with the President's budget.

Again, we would like to thank the Committee for its consideration of funding for programs to improve women's health, and we urge you to consider our MOMS Initiative in fiscal year 2012.

PREPARED STATEMENT OF THE AMERICAN DENTAL EDUCATION ASSOCIATION

The American Dental Education Association (ADEA)¹ respectfully submits this statement for the record and for your consideration as you begin to prioritize fiscal year 2012 appropriation requests. ADEA urges you to preserve the funding and fundamental structure of Federal programs that provide prevention of dental disease, access to oral healthcare for underserved populations, and access to careers in dentistry and oral health services.

As you know, ADEA's membership is comprised of all 61 dental schools in the United States. These academic dental institutions make substantial contributions to the oral health and well-being of the Nation. Services are provided through campus and offsite dental clinics where students and faculty provide patient care as dental homes to the uninsured and underserved populations. However, in order to continue to provide these services, there must be adequate funding. Therefore, it is critical that funding for oral healthcare, delivery of services, and research be preserved in order to ensure the level of care that is necessary for all segments of the population.

ADEA's requests build upon funding from the American Economic Recovery and Reinvestment Act (ARRA), the Labor, Health and Human Services and Education fiscal year 2010 Appropriations, and the Continuing Resolution for fiscal year 2011. We are asking the committee to maintain adequate funding for the dental programs in Title VII of the Public Health Service Act; the National Institutes of Health and the National Institute of Dental and Craniofacial Research; the Dental Health Improvement Act; Part F of the Ryan White HIV/AIDS Treatment and Modernization Act; the Dental Reimbursement Program and the Community-Based Dental Partnerships Program; and State-Based Oral Health Programs at the Centers for Disease Control and Prevention. These programs enhance and sustain State oral health departments, fund public health programs proven to prevent oral disease, fund research to eradicate dental disease, and fund programs to develop an adequate workforce of dentists with advanced training to serve all segments of the population including children, the elderly, and those suffering from chronic and life-threatening diseases.

\$30 million for Primary Oral Healthcare Workforce Improvements (HHS)

The dental programs in Title VII, Section 748 of the Public Health Service Act that provide training in general, pediatric, and public health dentistry and dental hygiene are critical. Support for these programs will help to ensure there will be an adequate oral healthcare workforce to care for the American public. The funding supports predoctoral oral health education and postdoctoral pediatric, general, and public health dentistry training. The investment that Title VII makes not only helps to educate dentists and dental hygienists, but also expands access to care for underserved communities.

Additionally, Section 748 addresses the shortage of professors in dental schools with the dental faculty loan repayment program and faculty development courses for those who teach pediatric, general, or public health dentistry or dental hygiene. There are currently almost 400 open faculty positions in dental schools. These two programs provide schools with assistance in recruiting and retaining faculty.

\$35 billion for the National Institutes of Health, including \$468 million for the National Institute of Dental and Craniofacial Research (NIDCR)

Discoveries stemming from dental research have reduced the burden of oral diseases, led to better oral health for millions of Americans, and uncovered important associations between oral and systemic health. Dental researchers are poised to make breakthroughs that can result in dramatic progress in medicine and health,

¹The American Dental Education Association represents all 61 U.S. dental schools, 700 dental residency training programs, nearly 600 allied dental programs, as well as more than 12,000 faculty who educate and train the nearly 50,000 students and residents attending these institutions. It is at these academic dental institutions that future practitioners and researchers gain their knowledge, where the majority of dental research is conducted, and where significant dental care is provided.

such as repairing natural form and function to faces destroyed by disease, accident, or war injuries; diagnosing systemic disease from saliva instead of blood samples; and deciphering the complex interactions and causes of oral health disparities involving social, economic, cultural, environmental, racial, ethnic, and biological factors. Dental research is the underpinning of the profession of dentistry. With grants from NIDCR, dental researchers in academic dental institutions have built a base of scientific and clinical knowledge that has been used to enhance the quality of the nation's oral health and overall health.

Also, dental scientists are putting science to work for the benefit of the healthcare system through translational research, comparative effectiveness research, health information technology, health research economics, and further research on health disparities. NIDCR continues to make disparities a priority with continued funding for the Centers for Research to Reduce Disparities in Oral Health at Boston University, the University of California, San Francisco, and the University of Colorado at Denver, the University of Florida, and the University of Washington.

\$20 million for the Dental Health Improvement Act (DHIA)

Section 340G of the Public Health Service Act created the Grants to States to Support Oral Health Workforce Activities as authorized by the Dental Health Improvement Act. This program supports the development of innovative dental workforce programs specific to the State's dental workforce needs and increases access to dental care for underserved populations.

In 2010, Congress provided a total of \$17.5 million to assist States in developing flexible dental workforce programs tailored to meet States' individual workforce needs. Grants are being used to support a variety of initiatives including, but not limited to: loan repayment programs to recruit culturally and linguistically competent dentists to work in underserved communities; rotating residents and students in rural areas; recruiting dental school faculty; training pediatricians and family medicine physicians to provide oral health services (screening exams, risk assessments, fluoride varnish application, parental counseling, and referral of high-risk patients to dentists); and supporting tele-dentistry. We expect fiscal year 2011 appropriations to continue to fund the fiscal year 2010 awarded grants, many of which are 3-year projects.

\$19 million for Part F of the Ryan White HIV/AIDS Treatment and Modernization Act: Dental Reimbursement Program (DRP) and the Community-Based Dental Partnerships Program

Patients with compromised immune systems are more prone to oral infections like periodontal disease and tooth decay. By providing reimbursement to dental schools and schools of dental hygiene, the Dental Reimbursement Program (DRP) provides access to quality dental care for people living with HIV/AIDS while simultaneously providing educational and training opportunities to dental residents, dental students, and dental hygiene students who deliver the care. DRP is a cost-effective Federal/institutional partnership that provides partial reimbursement to academic dental institutions for costs incurred in providing dental care to people living with HIV/AIDS. Congress, recognizing that dental care is a "core medical service" needed by HIV patients provided \$13.6 million to fund Part F in 2010.

\$107 million for Diversity and Student Aid

\$24 million for Centers of Excellence (COE)
 \$60 million for Scholarships for Disadvantaged Students (SDS)
 \$22 million for Health Careers Opportunity Program (HCOP)
 \$1.2 million for Faculty Loan Repayment Program (FLRP)

Title VII Diversity and Student Aid programs play a critical role in helping to diversify the health profession's student body and thereby the healthcare workforce. For the last several years, these programs have not enjoyed adequate funding to sustain the progress that is necessary to meet the challenges of an increasingly diverse U.S. population.

\$25 million for Oral Health Programs at the Centers for Disease Control and Prevention (CDC)

The CDC Oral Health Program expands the coverage of effective prevention programs. The program increases the basic capacity of State oral health programs to accurately assess the needs of the State, organize and evaluate prevention programs, develop coalitions, address oral health in state health plans, and effectively allocate resources to the programs. This strong public health response is needed to meet the challenges of oral disease affecting children, and vulnerable populations.

As the oral health programs at the CDC are so important, we have serious concerns about the proposal to downgrade the status of the Division of Oral Health

(DOH) at the CDC to a branch. We request that you do everything you can to prevent this move.

Thank you for your consideration of this request. ADEA looks forward to working with you to ensure the continuation of congressional support for these critical programs. Please feel free to use us a resource on any issue affecting the oral healthcare of the nation.

If you should have any questions regarding the aforementioned, please contact Deborah Darcy, ADEA Director of Congressional Affairs at (202) 289-7201 x 163.

PREPARED STATEMENT OF THE AMERICAN DENTAL HYGIENISTS' ASSOCIATION

On behalf of the American Dental Hygienists' Association (ADHA), thank you for the opportunity to submit testimony regarding appropriations for fiscal year 2012. ADHA appreciates the Subcommittee's past support of programs that seek to improve the oral health of Americans and to bolster the oral health workforce. Oral health is a part of total health and authorized oral healthcare programs require appropriations support in order to increase the accessibility of oral health services, particularly for the underserved.

ADHA is the largest national organization representing the professional interests of more than 152,000 licensed dental hygienists across the country. Dental hygienists are primary care providers of oral health services and are licensed in each of the 50 States. Hygienists are committed to improving the Nation's oral health, a fundamental part of overall health and general well-being. In order to become licensed as a dental hygienist, an individual must graduate from an accredited dental hygiene education program and successfully complete a national written and a State or regional clinical examination.

In the past decade, the link between oral health and total health has become more apparent and the significant disparities in access to oral healthcare services have been well documented. At the State and local level, policymakers and consumer advocates have been pioneering innovations to extend the reach of the oral healthcare delivery system and improve oral health infrastructure. At this time, when tens of millions of Americans struggle to obtain the oral healthcare required to remain healthy, Congress has a great opportunity to support oral health prevention, infrastructure and workforce efforts that will make care more accessible and cost-effective.

ADHA urges full funding of all authorized oral health programs and describes some of the key oral health programs below:

Title VII Program Grants to Expand and Educate the Dental Workforce—Fund at a level of \$25 million in fiscal year 2012

A number of existing grant programs offered under Title VII support health professions education programs, students, and faculty. ADHA is pleased that dental hygienists are now recognized as primary care providers of oral health services and are included as eligible to apply for several grants offered under the "General, Pediatric, and Public Health Dentistry" grants.

With millions more Americans eligible for dental coverage in coming years, it is critical that the oral health workforce is bolstered. Dental and dental hygiene education programs currently struggle with significant shortages in faculty and there is a dearth of providers pursuing careers in public health dentistry and pediatric dentistry. Securing appropriations to expand the Title VII grant offerings to additional dental hygienists and dentists will provide much needed support to programs, faculty, and students in the future.

ADHA recommends funding at a level of \$25 million for fiscal year 2012.

Alternative Dental Health Care Provider Demonstration Project Grants—Fund at a level of \$30 million in fiscal year 2012

States have increasingly been pioneering new dental delivery models to extend access to oral healthcare services to those currently unable to access needed care. The Alternative Dental Health Care Provider Demonstration Project grants support State-level efforts to better utilize the existing oral health workforce as well as develop new provider models.

A number of dental hygiene-based models are listed as eligible for the grants, including advanced practice hygienists, public health hygienists, and independent dental hygienists.

Grants could also be awarded to dental therapist models, programs where physicians/other medical providers deliver basic dental services and other models deemed appropriate by the Secretary of Health and Human Services. Funding would also

allow HRSA to fulfill its statutory requirement to contract with the Institute of Medicine to conduct a study of the demonstration projects.

Currently, more than 30 States have statutes and rules that allow dental hygienists to work in community-based settings (like public health clinics, schools, and nursing homes) to provide oral health services without the presence or direct supervision of a dentist. These models extend the reach of dental professionals beyond the private dental office.

The American Dental Education Association supports funding of this program. The PEW Charitable Trusts Children's Dental Campaign also supports funding of this program. Indeed, more than 60 organizations have called for funding this important program. Without the appropriate supply, diversity and distribution of the oral health workforce, the current oral health access crisis will only be exacerbated.

ADHA recommends funding at a level of \$30 million for fiscal year 2012 to support these vital demonstration projects.

Oral Health Prevention and Education Campaign—Fund at a level of \$5 million in fiscal year 2012

A targeted national campaign led by the Centers for Disease Control to educate the public, particularly those who are underserved, about the benefits of oral health prevention could vastly improve oral health literacy in the country. While significant data has emerged over the past decade drawing the link between oral health and systemic diseases like diabetes, heart disease, and stroke, many remain unaware that neglected oral health can have serious ramifications to their overall health. Data is also emerging to highlight the role that poor oral health in pregnant women has on their children, including a link between periodontal disease and low-birth weight babies.

ADHA advocates an allocation of \$5 million in fiscal year 2012 for a national oral health prevention and education campaign.

School-Based Sealant Programs—Fund at a level sufficient to ensure school-based sealant programs in all 50 States

Sealants have long-proven to be low-cost and effective in preventing dental caries (cavities), particularly in children. While most dental disease is fully preventable, dental caries remains the most common childhood disease, five times more common than asthma, and more than half of all children age 5–9 have a cavity or filling.

The CDC has noted that data collected in evaluations of school-based sealant programs indicates the programs are effective in stopping and preventing dental decay. Significant progress has been made in developing best practices for school-based sealant programs, yet most States lack well developed programs as a result of funding shortfalls. ADHA encourages the transfer of funding from the Public Health and Prevention Fund sufficient to allow CDC to meaningfully fund school-based sealant programs in all 50 States in fiscal year 2012.

Oral Health Programming within the Centers for Disease Control—Fund at a level of \$25 million in fiscal year 2012

ADHA joins with others in the dental community in urging \$25 million for oral health programming within the Centers for Disease Control. This funding level will enable CDC to continue its vital work to control and prevent oral disease, including vital work in community water fluoridation. Federal grants to facilitate improved oral health leadership at the State level, support the collection and synthesis of data regarding oral health coverage and access, promote the integrated delivery of oral health and other medical services, enable States to innovate new types of oral health programs and promote a data-driven approach to oral health programming.

ADHA joins with others in the oral health community to express concern with plans to fold the Division of Oral Health at CDC into the Division of Adult and Community Health, and asks the subcommittee to urge CDC to maintain the Division of Oral Health as a separate entity within the chronic disease center so that the Division of Oral Health can continue to improve the oral health of Americans from inception to old age.

ADHA advocates for \$25 million in funding for grants to improve and support oral health infrastructure and surveillance.

Dental Health Improvement Grants—Fund at a level of \$20 million in fiscal year 2012

HRSA administered dental health improvement grants are an important resource for States to have available to develop and carry out State oral health plans and related programs. Past grantees have used funds to better utilize the existing oral health workforce to achieve greater access to care. Previously awarded grants have funded efforts to increase diversity among oral health providers in Wisconsin, pro-

mote better utilization of the existing workforce including the extended care permit (ECP) dental hygienist in Kansas, and in Virginia implement a legislatively directed pilot program to allow patients to directly access dental hygiene services.

ADHA supports funding of HRSA dental health improvement grants at a level of \$20 million for fiscal year 2012.

National Institute of Dental and Craniofacial Research—Fund at a level of \$468 million in fiscal year 2012

The National Institute of Dental and Craniofacial Research (NIDCR) cultivates oral health research that has led to a greater understanding of oral diseases and their treatments and the link between oral health and overall health. Research breeds innovation and efficiency, both of which are vital to improving access to oral healthcare services and improved oral status of Americans in the future.

ADHA joins with others in the oral health community to support NIDCR funding at a level of \$468 million in fiscal year 2012.

Conclusion

ADHA appreciates the difficult task Appropriators face in prioritizing and funding the many meritorious programs and grants offered by the Federal Government. In addition to the items listed, ADHA joins other oral health organizations in support for continued funding of the Dental Reimbursement Program (DRP) and the Community-Based Dental Partnerships Program established under the Ryan White HIV/AIDS Treatment and Modernization Act (\$19 million for fiscal year 2012) as well as block grants offered by HRSA's Maternal Child Health Bureau (\$8 million for fiscal year 2012).

ADHA remains a committed partner in advocating for meaningful oral health programming that makes efficient use of the existing oral health workforce and delivers high quality, cost-effective care.

PREPARED STATEMENT OF THE AMERICAN DIABETES ASSOCIATION

Thank you for the opportunity to submit this testimony on behalf of the American Diabetes Association. As someone who has lived with diabetes for over thirty years, I am proud to be a representative of the nearly 105 million American adults and children living with diabetes or prediabetes.

Every minute, three more people are diagnosed with diabetes. While nearly 26 million Americans have diabetes today, this number is expected to grow to 44 million in the next 25 years if present trends continue. Every 24 hours, 230 people with diabetes will undergo an amputation, 120 people will enter end-stage kidney disease programs and 55 people will go blind from diabetes. Every single day, diabetes costs our country over a half a billion dollars, yet, that is but a fraction of the costs we face unless we immediately take action to stop the march of this epidemic.

Given the toll the diabetes epidemic imposes on the Nation's health and economy and the promise of public diabetes research and public health initiatives, the American Diabetes Association (Association) respectfully requests programs at the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) at the National Institutes of Health (NIH) and the Division of Diabetes Translation (DDT) at the Centers for Disease Control and Prevention (CDC) be top priorities in fiscal year 2012. As the Nation's leading non-profit health organization providing diabetes research, information and advocacy, the Association believes Federal funding for diabetes prevention and research is critical, not only for the 26 million American adults and children (8 percent of the population) who currently have diabetes, but for the 79 million more with prediabetes, a condition placing them at high risk for developing diabetes.

The Association acknowledges the challenging fiscal climate and supports fiscal responsibility, but not at the expense of America's health and well-being. Simply put, our country cannot afford the consequences of failing to adequately fund diabetes research and programs, a cost paid in expensive complications and death. We cannot afford to turn our backs on the promising research which provides tools to prevent diabetes, better manage it and prevent complications, and bring us closer to a cure.

Therefore, the Association urges the Senate LHHS Subcommittee to invest in research and prevention proportionate to the magnitude of the burden diabetes has on our country and, by doing so, to change the future of diabetes in America.

Diabetes is a chronic disease that impairs the body's ability to use food for energy. The hormone insulin, which is made in the pancreas, is needed for the body to change food into energy. In people with diabetes, either the pancreas does not create insulin, which is type 1 diabetes, or the body does not create enough insulin and/

or cells are resistant to insulin, which is type 2 diabetes. If left untreated, diabetes results in too much glucose in the blood stream. The majority of diabetes cases, 90 to 95 percent, are type 2, while type 1 diabetes accounts for 5 percent of diagnosed cases. Additionally, based on new diagnostic criteria, it is now estimated that 18 percent of pregnancies are affected by gestational diabetes. In the short term, blood glucose levels that are too high or too low (as a result of medication to treat diabetes) can be life threatening. The long-term complications of diabetes are widespread, serious—and deadly. In those with prediabetes, blood glucose levels are higher than normal and taking action to reduce their risk of developing diabetes is essential.

The Centers for Disease Control and Prevention (CDC) has identified diabetes as a disabling, deadly epidemic, which is on the rise. Between 1990 and 2001, the prevalence of diabetes increased by 60 percent. According to the CDC, one in three adults will have diabetes in 2050 if present trends continue. This number is even greater among minority populations, where nearly one in two adults will have diabetes in 2050.

Additionally, type 2 diabetes, traditionally seen in older patients, is beginning to reach a younger population, due in part to the surge in childhood obesity. Approximately one in every 400 children and adolescents has diabetes, and an alarming 2 million adolescents (or 1 in 6 overweight adolescents) aged 12–19 have prediabetes. The impact diabetes has on individuals and the healthcare system is enormous and continues to grow at a shocking rate. Diabetes is the leading cause of kidney failure, new cases of adult-onset blindness and non-traumatic lower limb amputations as well as a significant cause of heart disease and stroke.

In addition to the physical toll, diabetes also attacks our pocketbooks. A study by the Lewin Group found when factoring in the additional costs of undiagnosed diabetes, prediabetes, and gestational diabetes, the total cost of diabetes and related conditions in the United States in 2007 was \$218 billion (\$18 billion for undiagnosed diabetes; \$25 billion for prediabetes; \$623 million for gestational diabetes). In 2007, medical expenditures due to diabetes totaled \$116 billion, including \$27 billion for diabetes care, \$58 billion for chronic diabetes-related complications, and \$31 billion for excess general medical costs. Indirect costs resulting from increased absenteeism, reduced productivity, disease-related unemployment disability and loss of productive capacity due to early mortality totaled \$58 billion. Approximately one out of every five healthcare dollars is spent caring for someone with diagnosed diabetes, while one in ten healthcare dollars is directly attributed to diabetes. Further, one-third of Medicare expenses are associated with treating diabetes and its complications.

Despite these numbers, there is hope. A greater Federal investment in diabetes research at the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) at the National Institutes of Health (NIH), and prevention, surveillance, control, and research work currently being done at the Division of Diabetes Translation (DDT) at the CDC is crucial for finding a cure and improving the lives of those living with, or at risk for, diabetes. Additionally, the National Diabetes Prevention Program is poised to dramatically cut the number of new diabetes cases in high-risk individuals. Accordingly, for fiscal year 2012, the American Diabetes Association is requesting:

- \$2.209 billion for the NIDDK, an increase of \$267 million over the fiscal year 2011 level. This additional funding will act to offset years of decreased or flat funding combined with inflation that has led to cutbacks in promising research. It will also demonstrate Congress's commitment to science and research in the face of this deadly epidemic.
- \$86.1 million for the DDT, which represents a total increase of \$21.3 million over the fiscal year 2011 level for the DDT's critical prevention, surveillance and control programs. Even as proposals to consolidate the CDC's chronic disease programs including DDT circulate, expanded investment in the DDT will produce much larger savings in reduced acute, chronic, and emergency care spending.
- \$80 million for the implementation of the National Diabetes Prevention Program through the Prevention and Public Health Fund.

NIH's National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK)

The NIDDK is poised to make major discoveries to prevent diabetes, better treat its complications, and—ultimately—find a cure. Researchers supported by the NIH are working on a variety of projects representing hope for the millions of individuals with both type 1 and type 2 diabetes. While the list of advances in treatment and prevention is long, much more can be achieved for people with diabetes with an increased investment in scientific research at the NIDDK.

Thanks to research at the NIDDK, people with diabetes now manage their disease with a variety of insulin formulations and regimens far superior to those used in decades past. The result is the ability to live healthier lives with diabetes. Because of these advances, my hemoglobin A1C, which provides a snapshot of an individual's blood glucose, went from 12.9 percent, a very dangerous level, to 5.9 percent, an accomplishment that provides me with hope of avoiding diabetes's devastating complications. This is a dramatic development for me and proof of the importance of NIDDK's work.

Recent discoveries at the NIDDK include the ability to predict type 1 diabetes risk, new drug therapies for type 2 diabetes, and the discovery of genetic markers explaining the increased burden of kidney disease among African Americans. The NIDDK funded the Diabetes Prevention Program, a multicenter clinical research trial, which found modest weight loss through dietary changes and increased physical activity could prevent or delay the onset of type 2 diabetes by 58 percent. While great strides have been made in diabetes research, there are many unanswered questions about the disease meriting further study. Diabetes researchers across the country are poised to expand the base of knowledge of diabetes in order to make new discoveries transforming diabetes prevention and care.

Increased fiscal year 2012 funding would allow the NIDDK to support additional research in order to build upon past successes, improve prevention and treatment, and close in on a cure. For example, additional funding will support a new comparative effectiveness clinical trial testing different medications for type 2 diabetes, a process that is instrumental in finding the most effective treatments for type 2 diabetes. fiscal year 2012 funding will also support researchers who are studying how insulin-producing beta cells develop and function, with an ultimate goal of creating therapies for replacing damaged or destroyed beta cells in people with diabetes. Finally, additional funding will support ongoing studies outlining environmental triggers of disease, which could identify an infectious cause of type 1 diabetes and lead to a vaccine.

CDC's Division of Diabetes Translation (DDT)

The Senate Appropriations Committee's fiscal year 2011 bill provided increased resources to address chronic diseases through the creation of the Chronic Disease Initiative (CDI) at CDC. In approving the fiscal year 2011 LHHS bill, the full Committee acknowledged chronic disease programs, including the diabetes programs traditionally operated through the DDT, have been woefully underfunded to adequately address the trajectory and scope of diabetes and other diseases including heart disease, stroke and arthritis.

This year, ideas continue to circulate to consolidate programs at CDC, including DDT. While we think coordination across chronic disease programs at CDC is an important endeavor, Congress must ensure the needs of people with, and at risk for, diabetes are adequately addressed. Given DDT funding has not kept pace with the magnitude of the growing diabetes epidemic, the Federal investment in DDT programs should be substantially increased—at a minimum to \$86.1 million in fiscal year 2012—regardless of the organization of chronic disease programs at CDC or in any consolidation plan. As the dialogue continues about how best to address chronic disease prevention, DDT should be the centerpiece in the Federal Government's efforts in this regard and its State and national expertise should be maintained.

Preserving the DDT's expertise is vital. The Division works to eliminate the preventable burden of diabetes through proven educational programs, best practice guidelines and applied research. It performs vital work in both primary prevention of diabetes and in preventing its complications. Both key missions must continue. Funds appropriated to DDT focus on developing and maintaining State-based Diabetes Prevention and Control Programs (DPCPs), supporting the National Diabetes Education Program (NDEP), defining the diabetes burden through the use of public health surveillance, and translating research findings into clinical and public health practice. Our request of an additional \$21.3 million will allow these programs at DDT to reach more at-risk Americans and help to prevent or delay this destructive disease and its complications.

DDT's Diabetes Prevention and Control Programs, located in all 50 States, the District of Columbia, and U.S. territories, work to prevent diabetes, to lower blood glucose and cholesterol levels and to reduce diabetes-related emergency room visits and hospitalizations. DDT also plays a leadership role in the dissemination of diabetes prevention and treatment information through the National Diabetes Education Program, a joint effort of DDT and NIDDK. Funding for the DDT also supports vital and groundbreaking translational research like the Search for Diabetes in Youth study, collaboration between DDT and NIDDK designed to determine the impact of type 2 diabetes in youth in order to improve prevention efforts aimed at young peo-

ple. DDT is also engaged in efforts to eliminate diabetes related disparities in vulnerable populations that bear a disproportionate burden of the disease in urban and rural areas. Finally, DDT maintains vital diabetes data at the State and national levels through the National Diabetes Surveillance System, which helps determine how best to deploy resources in the most appropriate and cost-effective way.

Although DDT has played an instrumental role in fighting the diabetes epidemic, the reach of the Division could be significantly broader with additional fiscal year 2012 funding. With an additional \$21.3 million, the DDT will be able to expand the reach of DPCPs in every State and territory. Given the dramatic decreases in funding for State and local health departments, supporting the work of the DPCPs is more critical than ever to ensure access to diabetes care and services.

Increased funding for DDT is needed to allow the Division to build upon its work in reducing health disparities through vital programs such as the Native Diabetes Wellness Program, furthering the development of effective health promotion activities and messages tailored to American Indian/Native Alaskan communities. Additional resources will enable the DDT to expand its translational research studies, leading to improved public health interventions.

The National Diabetes Prevention Program

Further studies of the Diabetes Prevention Program by the CDC have shown this groundbreaking intervention can be replicated in community settings for a cost of less than \$300 per participant. With this in mind, the National Diabetes Prevention Program was authorized by the Patient Protection and Affordable Care Act of 2010. This program will provide funding to the CDC to expand such evidence-based programs across the country. We ask the Committee to direct \$80 million from the Fund for the National Diabetes Prevention Program.

The National Diabetes Prevention Program supports the creation of community-based sites where trained staff will provide those at high risk for diabetes with cost-effective, group-based lifestyle intervention programs. Local sites will be required to provide detailed program plans, ensure adequate training, and be rigorously evaluated based on the achievement of required standards and goals. The program also includes applied research grants, which will advance the national strategy for community-based programs and improve communication strategies for high-risk communities.

The Fund seeks to make a national investment in prevention and public health programs, both to improve the health of Americans and to rein in healthcare costs. The National Diabetes Prevention Program is exactly the program the Fund should be supporting. The NIH did research in the clinical setting—it worked. The CDC translated this research to the community setting—it worked. It is an amazingly inexpensive proven means of combating a growing epidemic. Indeed, the Urban Institute has estimated a nationwide expansion of this type of diabetes prevention program will save a total of \$190 billion over 10 years. Based on estimates that a large portion of burden of chronic disease falls on the poor and elderly, the Institute's report assumes 75 percent of this savings would be savings to Medicare or Medicaid.

Conclusion

As you consider the fiscal year 2012 appropriation for NIDDK, and DDT, and the National Diabetes Prevention Program, we ask you to consider diabetes is an epidemic growing at an astonishing rate, which will overwhelm the healthcare system with tragic consequences unless we take action. To change this future, we must increase our commitment to research and prevention to reflect the burden diabetes poses both for us and for our children. Our fight against diabetes must be significantly expanded. Your leadership in combating this growing epidemic is essential. Thank you for your commitment to the diabetes community and for the opportunity to submit this testimony. The Association is prepared to answer any questions you might have on these important issues.

PREPARED STATEMENT OF THE AMERICAN FOUNDATION FOR SUICIDE PREVENTION

Chairman Harkin, Ranking Member Shelby and members of the Committee. The American Foundation for Suicide Prevention (AFSP) thanks you for the opportunity to provide testimony on the funding needs of Federal Agencies and programs that play a critical role in suicide prevention efforts.

AFSP is the leading national not-for-profit organization exclusively dedicated to understanding and preventing suicide through research, education and advocacy, and to reaching out to people with mental disorders and those impacted by suicide. You can find more information at www.asfp.org and www.spanusa.org.

Preliminary data from the Centers for Disease Control for 2009 shows that suicide is the 10th leading cause of death in the United States (36,547) and the third leading cause of death in teens and young adults from ages 15–24. Nearly 1.1 million Americans attempt suicide each year and another 8 million have suicidal thoughts. Suicide in 1 year costs the United States \$13 billion in lost earnings, 1 million years of lost life and suicide attempts requiring hospitalization amount to \$3.54 billion in lost medical and work-loss costs.

In order to more effectively combat this public health crisis, AFSP urges the Committee approve funding at the levels requested for the following programs/agencies for fiscal year 2012:

Garrett Lee Smith Memorial Act Programs

We respectfully request that Garrett Lee Smith Memorial Act (GLSMA) youth suicide prevention grant programs receive \$53.2 million for fiscal year 2012.

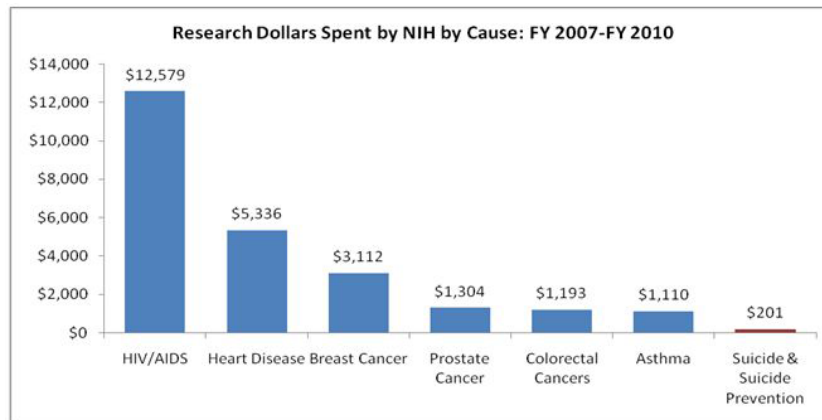
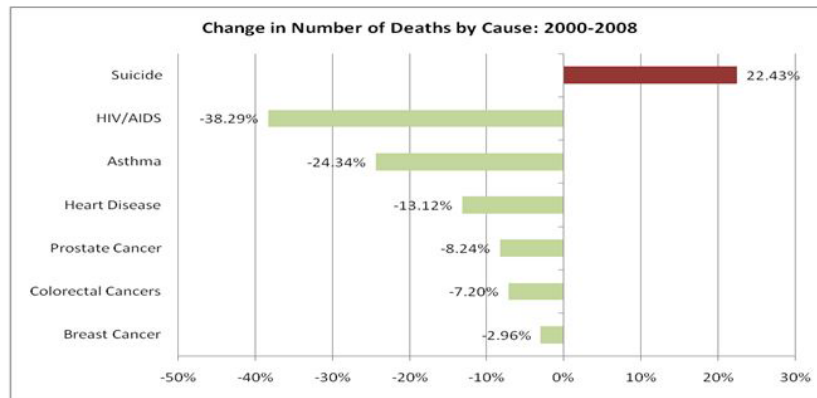
Since 2005, the Substance Abuse and Mental Health Services Administration (SAMHSA) has awarded GLSMA grants to 45 State programs, 12 tribal programs, and 78 colleges and universities for programs to help reduce youth suicides rates. State grantees include: Alaska, Arizona, Colorado, Connecticut, District of Columbia, Delaware, Florida, Georgia, Guam, Hawaii, Iowa, Idaho, Indiana, Kentucky, Louisiana, Massachusetts, Maryland, Maine, Michigan, Missouri, Mississippi, North Carolina, North Dakota, Nebraska, New Hampshire, New Mexico, Nevada, New York, Ohio, Oklahoma, Oregon, Pennsylvania, Rhode Island, South Carolina, South Dakota, Tennessee, Texas, Utah, Virginia, Vermont, Washington, Wisconsin, West Virginia, and Wyoming.

Funding for the Act is directed to three programs administered by SAMHSA. We request \$5 million for the Suicide Prevention Technical Assistance Center to support its mission of providing technical assistance and support to grantees. We request \$42 million for the Youth Suicide Early Intervention and Prevention Strategies grant program. These grants help States and tribes develop and implement statewide youth suicide early intervention and prevention strategies that will raise awareness and educate people about mental illness and the risk of suicide, help young people at risk of suicide take the first step toward seeking help, and allow States to expand access to treatment options. Finally, we request \$6.2 million to fund the Mental and Behavioral Health Services on Campus matching-grant program for colleges and universities to help raise awareness about youth suicide, as well as enable those institutions to train students and faculty to identify and intervene when youth are in crisis, and develop a system to refer students for care.

Support Federal Investment in Suicide Prevention Research at NIMH for Fiscal Year 2012

Strategic investments in disease research have produced declines in deaths, and the same types of investments are necessary to reduce deaths by suicide. In fiscal year 2010 (latest data) only \$41 million was devoted directly to suicide research. AFSP urges Congress to increase the investment in suicide prevention research at the National Institutes of Mental Health by 15 percent, or \$6.15 million.

It is illuminating to compare the number of suicide deaths with the number of deaths in several major disease categories against the direct dollars spent on research in those areas (see below). In fact, the Institute of Medicine, in their 2002 report “Reducing Suicide: A National Imperative,” stated the following: “There is every reason to expect that a national consensus to declare war on suicide and to fund research and prevention at a level commensurate with the severity of the problem will be successful, and will lead to highly significant discoveries as have the wars on cancer, Alzheimer’s disease, and AIDS.”



Maintain Vital Funding for SAMHSA Suicide Prevention Programs and Mental Health Services

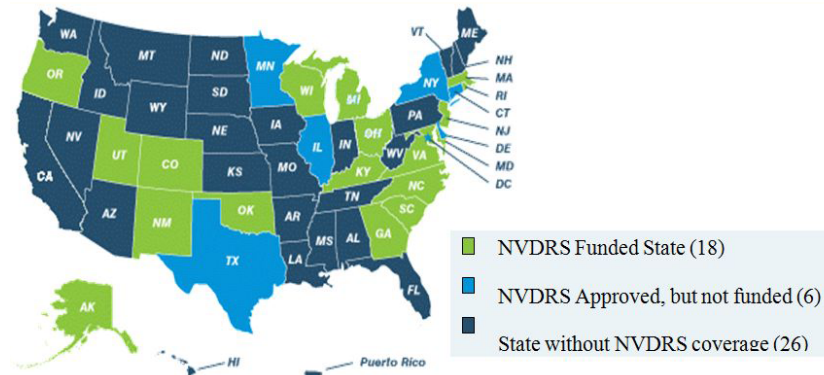
As the lead Government agency charged with implementation of suicide prevention initiatives, AFSP urges this Committee to provide \$3.387 billion for SAMHSA in fiscal year 2012. By this action Congress will recognize the important role SAMHSA plays in healthcare delivery and mental health services.

As the lead Government agency charged with implementation of suicide prevention initiatives, SAMHSA has supported the establishment of a national toll-free hotline (the National Suicide Prevention Lifeline), a technical assistance center (the Suicide Prevention Resource Center), and a youth suicide prevention grant program for States and colleges (authorized and funded under the Garrett Lee Smith Memorial Act). Since its launch in January 2005, the Suicide Prevention Lifeline has answered more than 1 million calls and has 140 active crisis centers in 48 States. Beginning in 2008, SAMHSA's National Survey on Drug Use and Health asked respondents about suicide attempts and whether or not they had previously acknowledged major depression. This was an important first step forward in suicide surveillance, promoting greater attention to the interrelationship of suicide, substance abuse and depression. Moreover, the Agency also has been supporting the identification, development and promotion of best practices in suicide prevention, focusing on risk and protective factors related to suicide, with particular attention to mental health and substance abuse issues affecting suicide risk.

Support Federal Investment in Data Collection in Fiscal Year 2012

To design effective suicide prevention strategies, we must first have complete, accurate and timely information about deaths by suicide. The National Violent Death Reporting System (NVDRS) provides this information, which is essential to improve

State and Federal suicide prevention activities. Current funding of \$3.5 million allows only 18 States to participate in this program. This Committee approved an additional \$1.5 million in fiscal year 2011; however, the bill never got signed into law. AFSP urges this Committee to appropriate the full \$5 million for the NVDRS in fiscal year 2012.



Provide Funding for Depression Centers of Excellence (DCOE)

This Committee included \$10 million for the DCOE in the fiscal year 2011 mark up as a down payment toward studying Depression, the most common psychiatric diagnosis associated with suicide. AFSP urges Congress to appropriate funds to the DCOE at the highest levels possible in fiscal year 2012.

Depression Centers of Excellence would increase access to the most appropriate and evidence-based depression care and develop and disseminate evidence-based treatment standards to improve accurate and timely diagnosis of depression and bipolar disorders. Additionally, they would create a national database for large-sample effectiveness studies and a repository of evidence-based interventions and programs for depression and bipolar disorders. They would also utilize the network of centers as an ongoing national resource for public and professional education and training, with the goal of advancing knowledge and eradicating stigma of these mental disorders.

Chairman Harkin, Ranking Member Shelby and Members of the Committee. AFSP once again thanks you for the opportunity to provide testimony on the funding needs of Federal Agencies and programs that play a critical role in suicide prevention efforts.

Suicide robs families, communities and societies of tens of thousands of its citizens. In a single year, in the United States alone, suicide is responsible for the deaths of over 36,000 people of all ages and costs an estimated \$13 billion in lost income. With your help, we can assure those tasked with leading the Federal Government's response to this public health crisis will have the resources necessary to effectively prevent suicide.

PREPARED STATEMENT OF THE AMERICAN GERIATRICS SOCIETY

Mr. Chairman and Members of the Subcommittee: We are writing on behalf of the American Geriatrics Society (AGS), a nonprofit organization of over 6,000 geriatrics healthcare professionals dedicated to improving the health, independence and quality of life of all older Americans. As the Subcommittee begins to work on its Labor-HHS-Education Appropriations bill, we ask that you prioritize funding for the geriatrics education and training programs under Title VII and Title VIII of the Public Health Service Act and for research funding within the National Institute on Aging in fiscal year 2012.

Continued Federal investments are needed to support the training of the healthcare workforce and to foster groundbreaking medical research so that our Nation is prepared to meet the unique healthcare needs of the rapidly growing population of seniors. While we fully recognize the fiscal challenges facing our Nation, we also recognize that sustained and enhanced Federal investments in these initiatives are essential to fulfilling the promise of health reform to deliver higher quality and better coordinated care to our Nation's seniors.

We ask that the subcommittee consider the following recommended funding levels for these programs in fiscal year 2012: \$46.5 million for Title VII Geriatrics Health Professions Programs, \$5 million for Title VIII Comprehensive Geriatric Education Nursing Program, and \$1.4 billion for the National Institute on Aging.

Summarized and broken down below are the American Geriatrics Society's funding priorities in these areas for fiscal year 2012.

Programs to Train Geriatrics Health Care Professionals

This year, the first wave of baby boomers turn 65, signaling the start of a significant demographic shift in America's population. According to the Institute of Medicine's (IOM) ground-breaking 2008 report, *Retooling for an Aging America: Building the Healthcare Workforce*, America's healthcare workforce is woefully ill-prepared to care for the growing and unprecedented number of seniors, especially those with multiple chronic and complex medical conditions.

The increase in the older adult population is expected to be even greater in rural America, which are more likely to experience poor health and a shortage of healthcare resources. Not only are geriatricians few in number, but they are largely concentrated in urban areas. Of further concern, our Nation is facing a critical shortage of geriatrics faculty and healthcare professionals across disciplines. At the same time, the Title VII and VIII geriatrics programs under the Public Health Service Act have remained essentially level-funded since fiscal year 2007 and in each subsequent year the geriatrics programs have received an even smaller percentage of funding provided to Title VII and VIII programs.

This trend must be reversed if we are to provide our seniors with the quality care they need and deserve. AGS believes it is critical that Congress increase the percentage of Title VII and VIII funding that is devoted to supporting increasing the capacity of America's healthcare workforce to care for older adults. Care provided by geriatric healthcare professionals, who understand the most complex cases and the most frail elderly, has shown to reduce those common and costly conditions that are often preventable with appropriate care, such as falls, polypharmacy, and delirium.

Title VII Geriatrics Health Professions Programs (\$46.5 million)

Funding for Title VII Geriatrics Health Professions Programs is a proven investment in ensuring that older adults receive high quality healthcare now and in the future. These programs support three initiatives: the Geriatric Academic Career Awards (GACAs), the Geriatric Education Center (GEC) program, and geriatric faculty fellowships, the only programs specifically designed to address the evident shortage of geriatrics healthcare professionals in the United States. Strong and sustained investments are important to reversing the chronic under-funding of these essential programs at a time when our Nation is facing a critical shortage of geriatrics healthcare professionals across disciplines. We ask the subcommittee to provide a fiscal year 2012 appropriation of \$46.5 million for Title VII Geriatrics Health Professions Programs.

Our funding request of \$46.5 million breaks down as follows:

—*Geriatric Academic Career Awards (GACAs) (\$5.3 million).*—GACAs support the development of newly trained geriatric physicians in academic medicine who are committed to teaching geriatrics in medical schools across the country. GACA recipients are required to provide training in clinical geriatrics, including the training of interdisciplinary teams of healthcare professionals. Under ACA, GACAs have been expanded to a variety of new disciplines beyond physicians, including those in nursing, social work, psychology, dentistry, and pharmacy. AGS has long advocated for this change. We must now ensure that there is adequate funding to meet the increased demand given the greater number of disciplines eligible for the award. A budget of \$5.3 million would support 68 award-ees at \$78,000 per award.

—*Program Accomplishments.*—In Academic Year 2009–2010, there were 84 non-competing continuation awards. GACA awardees provided interdisciplinary training in geriatrics training to about 60,000 health professionals. These awardees provided culturally competent quality healthcare to over 525,000 underserved and uninsured patients in acute care services, geriatric ambulatory care, long-term care, and geriatric consultation services settings.

—*Geriatric Education Centers (GECs) (\$22.7 million).*—GECs provide grants to support collaborative arrangements involving several health professions, schools and healthcare facilities to provide multidisciplinary training in geriatrics, including assessment, chronic disease syndromes, care planning, emergency preparedness, and cultural competence unique to older Americans. Under ACA, Congress authorized \$10.8 million over 3 years for a supplemental grant award

program that will train additional faculty through an intensive short-term fellowship program and also requires faculty to provide training to family caregivers and direct-care workers. Our funding request of \$22.7 million includes continued support for the core work of 45 GECs and for up to 24 GECs to be funded to undertake the work through the supplemental grant program.

Program Accomplishments.—In Academic Year 2009–2010, the GEC grantees provided clinical training to 54,167 health professional students and to 20,791 interdisciplinary teams in multiple settings.

—*Geriatric Training Program for Physicians, Dentists, and Behavioral and Mental Health Professions (\$8.5 million).*—This program is designed to train physicians, dentists, and behavioral and mental health professionals who choose to teach geriatric medicine, dentistry or psychiatry. The program provides fellows with exposure to older adult patients in various levels of wellness and functioning, and from a range of socioeconomic and racial/ethnic backgrounds. Our funding request of \$8.5 million will allow 13 institutions to continue this important faculty development program.

Program Accomplishments.—In Academic Year 2009–2010, 11 non-competing continuation grants were supported. Forty-nine physicians, dentists, and psychiatric fellows provided geriatric care to 20,078 older adults across the care continuum. Geriatric physician fellows provided healthcare to 12, 254 older adults. Geriatric dental fellows provided healthcare to 4,073 older adults. Geriatric psychiatry fellows provided healthcare to 3,751 older adults.

—*Geriatric Career Incentive Awards Program (\$10 million).*—This is a new grant award program created under ACA to foster greater interest among a variety of health professionals in entering the field of geriatrics, long-term care, and chronic care management. AGS supports the President's fiscal year 2012 request of \$10 million to implement this new program.

Title VIII Comprehensive Geriatric Education Nursing Program (\$5 million)

The American healthcare delivery system for older adults will be further strengthened by Federal investments in Title VIII Nursing Workforce Development Programs, specifically the comprehensive geriatric education grants, as nurses provide cost-effective, quality care. Increasing funding for the nursing comprehensive geriatric education program would be highly cost effective. This program supports additional training for nurses who care for the elderly, development and dissemination of curricula relating to geriatric care, and training of faculty in geriatrics. It also provides continuing education for nurses practicing in geriatrics.

Under the new health reform law, this program is being expanded to include advanced practice nurses who are pursuing long-term care, geropsychiatric nursing or other nursing areas that specialize in the care of older adults. Our funding request of \$5 million includes funds to continue the training of nurses caring for older Americans offer 200 traineeships to nurses under this newly expanded program.

Program Accomplishments.—In Academic Year 2009–2010, 27 CGEP grantees provided education and training to 3,030 Registered Nurses/Registered Nursing Students; 260 Advanced Practice Nurses; 221 Faculty; 110 Home Health Aides; 483 Licensed Practical/Vocational Nurses & LPN students; 730 Nurse Assistants/Patient Care Associates; 810 Allied Health Professionals and 929 lay persons, guardians, activity directors. The CGEP grantees provided 459 educational course offerings in the care of the elderly on a variety of topics to 6,846 participants.

Research Funding Initiatives

National Institute on Aging (\$1.4 billion)

The NIA leads a broad scientific effort to understand the nature of aging and to extend the healthy, active years of life. Robust medical research in aging is critical to the development of medical advances which will ultimately lead to higher quality and more efficient healthcare. Continued Federal investments in scientific research, including comparative effectiveness initiatives, will ensure that the NIA has the resources to succeed in its mission to establish research networks, assess clinical interventions and disseminate credible research findings to patients, providers and payers of healthcare.

As a member of the Friends of the NIA, a broad-based coalition of more than 45 aging, disease, research, and patient groups committed to the advancement of medical research that affects millions of older Americans, AGS asks that NIA receive \$1.4 billion in fiscal year 2012. Alternatively, in light of our Nation's immediate budget constraints, we request that that the NIA be funded at no less than the \$1.29 billion, as requested in the President's fiscal year 2012 budget.

According to the Congressional Research Service, in fiscal year 2003, NIH reached the peak of its purchasing power from regular appropriations when Congress com-

pleted a 5-year doubling of the NIH budget. In each year since then, NIH's buying power has declined because its annual appropriations have grown at a lower rate than the inflation rate for medical research.

Essentially flat funding of NIH since 2003 has additionally led to declining numbers of young investigators choosing research careers, given the scarcity of funding to support their career development. We must provide the resources and tools to support the next generation of investigators and expand the pool of clinical researchers focused on advancing aging research.

The ongoing Federal commitment to investments in science, research, and technology lead to cutting-edge breakthroughs in medicine and improved patient care. AGS urges Congress to maintain this commitment in fiscal year 2012 and beyond, so that we may continue to advance medicine to improve the quality of care of our Nation's older adults and the long-term goals of health reform can be fully achieved.

In closing, geriatrics is at a critical juncture, with our Nation facing an unprecedented increase in the number of older patients with complex health needs. Strong support such as yours will help ensure that the promise of health reform is fulfilled and every older American is able to receive high-quality healthcare.

Thank you for your consideration.

PREPARED STATEMENT OF THE AMERICAN HEART ASSOCIATION

Over the past 50 years, major progress has been made in the battle against heart disease, stroke and other forms of cardiovascular disease (CVD). Improved diagnosis and treatment have been remarkable—as has the survival rate. According to the National Institutes of Health (NIH), since the 1960s, 1.6 million lives have been saved that would have been lost to CVD. Americans can now expect to live on average 4 years longer due to the reduction in heart-related deaths.

Yet, one startling fact remains. Heart disease and stroke are still respectively the No. 1 and No. 3 killers in the United States. Nearly 2,200 people die of CVD each day—one death every 39 seconds. CVD is a major cause of disability and costs our Nation more than any disease—a projected \$287 billion in medical expenses and lost productivity for 2007. Today, an estimated 83 million adults suffer from CVD. Moreover, CVD risk factors such as obesity and high blood pressure are on the rise. At age 40, the lifetime risk for CVD is 2 in 3 for men and over 1 in 2 for women.

Moreover, a new study projects that more than 40 percent of adults in the United States will live with the consequences of CVD at a cost to exceed \$1 trillion annually by the year 2030. The graying of Americans combined with the explosive growth in medical spending are the main drivers of increased costs. Our country is truly facing a crisis. Without prevention on a nationwide scale, managing CVD will be an enormous challenge. Clearly, there must be a greater emphasis on prevention and evidence-based approaches to healthy behaviors. This will require strategies to reach people where they live, work and play. Prevention must be an integral part of our toolkit to promote heart healthy and stroke-free habits and wellness at an early age.

Yet, in the face of these statistics, heart disease and stroke research, treatment and prevention programs remain woefully underfunded and money for NIH is unpredictable for the continuity of effort needed for key advances to redefine disease, ramp up prevention and promote best care.

Given CVD is the No. 1 killer in each State and preventable and treatable risk factors continue to rise, many are surprised that the Centers for Disease Control and Prevention (CDC) invests on average only 16 cents per person on heart disease and stroke prevention. Also, only 20 States are funded for WISEWOMAN—a proven heart disease and stroke prevention program that serves uninsured and under-insured low-income women with a high prevalence of CVD risk factors.

Where you live could also affect if you survive a very deadly form of heart disease—sudden cardiac arrest (SCA). Only 21 States received funding in fiscal year 2010 for the Health Resources and Services Administration's (HRSA) Rural and Community Access to Emergency Devices Program designed to save lives from sudden cardiac death.

The American Heart Association applauds the administration and Congress for providing hope to the 1 in 3 adults in the United States who live with CVD by wisely investing in the NIH and in the Prevention and Public Health Fund. These resources have provided a much needed boost to improve our Nation's physical and fiscal health. However, stable and sustained funding is critical for fiscal year 2012 to advance heart disease and stroke research, prevention and treatment.

FUNDING RECOMMENDATIONS: INVESTING IN THE HEALTH OF OUR NATION

Heart disease and stroke risk factors continue to rise, yet promising research to stem this tide goes unfunded. Too many Americans die from CVD, while proven prevention efforts beg for resources for widespread implementation. Now is the time to boost research, prevention and treatment of America's No. 1 and most costly killer. If Congress fails to build on progress of the past half century, Americans will pay more in lives lost and higher healthcare costs. Our recommendations address these issues in a comprehensive and fiscally responsible manner.

Capitalize on Investment for the National Institutes of Health (NIH)

NIH research has revolutionized patient care and holds the key to finding new ways to prevent, treat and even cure CVD, resulting in longer, healthier lives and reduced healthcare costs. NIH invests resources in every State and in 90 percent of congressional districts. According to a 2008 study, the typical NIH grant paid the salaries of about 7 mainly high-tech full-time or part-time jobs in fiscal year 2007. Further, every dollar that NIH distributes in a grant returns \$2.21 in goods and services to the local community in 1 year.

American Heart Association Advocates.—We advocate for a fiscal year 2012 appropriation of \$35 billion for NIH to capitalize on the investment to save lives, advance better health, spur our economy and spark innovation. NIH research prevents and cures disease, generates economic growth and preserves the U.S. role as the world leader in pharmaceuticals and biotechnology.

Enhance Funding for NIH Heart and Stroke Research: A Proven and Wise Investment

From 1997 to 2007, death rates for coronary heart disease and stroke fell nearly 28 percent and 45 percent, respectively. However, there is still much more to be done to improve the lives of heart disease and stroke patients—and more importantly to prevent CVD and stroke in the first place. Research will help lead the way. These declines in mortality are directly related to NIH heart and stroke research, with scientists on the verge of exciting discoveries that could lead to new treatments and even cures. For example, the biggest U.S. stroke rehabilitation study showed that patients who receive home physical therapy improve walking skills just as effectively as those treated in a program and that the progress continued up to 1 year post-stroke. NIH research has also demonstrated that over-zealous blood pressure lowering and combination lipid drugs did not cut cardiovascular disease in adult diabetics more than standard evidence-based care. Moreover, studies have defined the genetic basis of risky responses to vital blood-thinners.

In addition to saving lives, NIH-funded research can cut healthcare costs. For example, the original NIH tPA drug trial resulted in a 10-year net \$6.47 billion reduction in stroke healthcare costs. Also, the Stroke Prevention in Atrial Fibrillation Trial 1 produced a 10-year net savings of \$1.27 billion. Yet, in the face of such solid returns on investments and other successes, NIH still invests a meager 4 percent of its budget on heart research, and a mere 1 percent on stroke research.

Cardiovascular Disease Research: National Heart, Lung, and Blood Institute (NHLBI)

Even in the face of progress and promising research opportunities, there is no cure for CVD. As our population ages, demand will only increase to find better ways for Americans to live healthy and productive lives despite CVD. Stable and sustained funding is needed to allow NHLBI to build on investments that provided grants to use genetics to identify and treat those at greatest risk from heart disease; hasten drug development to treat high cholesterol and high blood pressure; and create tailored strategies to treat, slow or prevent heart failure. Other key studies include an analysis of whether maintaining a lower blood pressure than currently recommended further reduces risk of heart disease, stroke, and cognitive decline. This information is vital to manage the burden of heart disease and stroke. Sustained critical funding will allow for aggressive implementation of other initiatives in the NHLBI and cardiovascular strategic plans.

Stroke Research: National Institute of Neurological Disorders and Stroke (NINDS)

An estimated 795,000 people in this country will suffer a stroke this year, and more than 135,950 will die. Many of the 7 million survivors face severe physical and mental disabilities, emotional distress and huge costs—a projected \$41 billion in medical expenses and lost productivity for 2007. A new study projects stroke prevalence will increase 25 percent over the next 20 years, striking more than 10 million individuals. Over the same time period, direct medical costs will rise 238 percent.

Stable and sustained funding is required for NINDS to capitalize on investments to prevent stroke, protect the brain from damage and enhance rehabilitation. This includes initiatives to: (1) determine if MRI brain imaging can assist in selecting stroke victims who could benefit from the clot busting drug tPA beyond the 3-hour treatment window; (2) assess chemical compounds that might shield brain cells during a stroke; and (3) advance stroke rehabilitation by studying if the brain can be helped to “rewire” itself after a stroke. Enhanced funding will also allow for proactive initiation and implementation of the NINDS’ novel stroke planning process (a result of its Stroke Progress Review Group) to assess the stroke research field and develop priorities to advance the most promising prevention, treatment, recovery and rehabilitation research.

The American Heart Association Advocates.—While AHA supports increased funding for the 18 Institutes and centers that conduct heart and stroke research, including the National Institute of Diabetes, and Digestive and Kidney Diseases; and the National Institute on Aging, we have specific funding recommendations for the NHLBI and the NINDS. AHA advocates for an fiscal year 2012 appropriation of \$3.514 billion for NHLBI; and \$1.857 billion for NINDS.

Increase Funding for the Centers for Disease Control and Prevention (CDC)

Prevention is the best way to protect the health of all Americans and reduce the economic burden of CVD. Yet, effective prevention strategies and programs are not being implemented due to insufficient resources. The President’s 2012 budget proposes a Coordinated Chronic Disease Prevention and Health Promotion Grant Program. AHA supports some consolidation of chronic disease programs, but with some important modifications and caveats. First, CDC must preserve the Division for Heart Disease and Stroke Prevention. A consolidation must ensure more predictable and adequate funding to all 50 States, including an annual share of the Prevention and Public Health Fund, with resources allocated by formula on the basis of burden, including cost, mortality, morbidity, and prevalence. These programs must be evidence-based and targeted, with a focus on capacity, evaluation and surveillance, including measurable outcomes and a higher level of accountability. To preserve the best elements of existing programs, funding should preserve evidenced-based outcomes work across the full spectrum of prevention and clinical care, including primary and secondary prevention, acute treatment, rehabilitation and continuous quality improvement (CQI). Each State must retain staff expertise to effectively address heart disease and stroke. State-based advisory groups of stakeholders from each constituency should be formed to help with plan implementation. A national advisory committee of constituencies should be created to foster stakeholder involvement. Matches, including in-kind, should be required when possible to build support in State health departments. Plans should use some funding for at least one program on common risk factors to consolidated diseases that can show a measurable, population-based impact. The rest of the funds should be spent on effective, evidence-based projects aimed at secondary prevention, acute treatment, rehabilitation, and CQI.

This CDC division administers WISEWOMAN that serves uninsured and underinsured low-income women ages 40 to 64 in 20 States. This program helps them avoid heart disease and stroke by providing preventive health services, referrals to local healthcare providers, as needed, and lifestyle counseling and interventions tailored to their identified risk factors to promote lasting, healthy behavior modifications. From July 2008 to June 2010, WISEWOMAN reached more than 70,000 low-income women. During this time period, 89 percent of them had a least one risk factor and 28 percent had three or more risk factors for heart disease and stroke. However, more than 43,000 of these women participated in at least one lifestyle intervention session.

The American Heart Association Advocates.—AHA joins with the CDC Coalition in advocating for \$7.7 billion for the CDC’s “core programs,” including increases for the Division of Heart Disease and Stroke Prevention and WISEWOMAN. AHA recommends \$37 million to expand WISEWOMAN to more States and serve more eligible women in already funded States. We join the Friends of the NCHS in asking for \$162 million for the National Center for Health Statistics.

Restore Funding for Rural and Community Access to Emergency Devices (AED) Program

About 92 percent of sudden cardiac arrest (SCA) victims die outside of a hospital. But, prompt CPR and defibrillation, with an automated external defibrillator (AED), can more than double their chances of survival. Communities with comprehensive AED programs have reached survival rates of about 40 percent. HRSA’s Rural and Community AED Program provides grants to States, competitively, to buy AEDs,

train lay rescuers and first responders in their use and place AEDs where SCA is likely to occur. From September 2007 to August 2008, 3,051 AEDs were bought and 10,287 people were trained. And, 795 patients were saved between August 1, 2009 and July 31, 2010. Due to insufficient budgets, only 21 states received funds for this program in fiscal year 2010.

The American Heart Association Advocates.—For fiscal year 2012, AHA advocates restoring HRSA's Rural and Community AED Program to its fiscal year 2005 level of \$8.927 million.

Increase Funding for the Agency for Healthcare Research and Quality (AHRQ)

AHRQ develops scientific evidence to improve healthcare for Americans. AHRQ provides patients and caregivers with valuable scientific evidence to make the right healthcare decisions. AHRQ's research also enhances quality and efficiency of healthcare, providing the basis for protocols that prevent medical errors and reduce hospital-acquired infections, and improve patient confidence, experiences, and outcomes.

The American Heart Association Advocates.—AHA joins Friends of AHRQ in advocating for \$405 million for AHRQ to preserve its vital initiatives, boost the research infrastructure, spur innovation, nurture the next generation of scientists and help reinvent health and healthcare.

CONCLUSION

Cardiovascular disease continues to inflict a deadly, disabling and costly toll on Americans. Yet, our funding recommendations for NIH, CDC and HRSA outlined above will save lives and cut rising healthcare costs. The American Heart Association urges Congress to seriously consider our suggestions during the fiscal year 2012 appropriations process. These proposed resources represent a wise investment for our nation and for the health and well-being of this and future generations.

PREPARED STATEMENT OF THE AMERICAN INDIAN HIGHER EDUCATION CONSORTIUM

Summary of Requests.—Summarized below are the fiscal year 2012 recommendations of the Nation's Tribal Colleges and Universities (TCUs), covering three areas within the Department of Education and one in the Department of Health and Human Services, Administration for Children and Families' Head Start Program.

DEPARTMENT OF EDUCATION PROGRAMS

Higher Education Act Programs

Strengthening Developing Institutions.—Section 316 of HEA Title III–A, specifically supports TCUs' grant programs. The TCUs request that the Subcommittee appropriate \$30 million for this critically important program, the same level included in the President's fiscal year 2012 budget request.

TRIO Programs.—Retention and support services are vital to achieving the national goal of having the highest percentage of college graduates globally by 2020. The President's fiscal year 2012 budget request includes funding for TRIO programs at fiscal year 2010 levels, which is not enough to sustain even the current level of program services. The TCUs support building on the President's fiscal year 2012 budget request for TRIO programs and technical assistance funding so that these essential program services can be, at a minimum, maintained at current levels.

Pell Grants.—TCUs urge the Subcommittee to sustain the current Pell Grant maximum.

Perkins Career and Technical Education Programs

Section 117 of the Carl D. Perkins Career and Technical Education Act provides a competitively awarded grant opportunity for tribally chartered and controlled career and technical institutions. AIHEC requests \$8,200,000 to fund grants under Section 117 of the Perkins Act. Additionally, TCUs strongly support the Native American Career and Technical Education Program (NACTEP) authorized under Section 116 of the Perkins Act.

Elementary and Secondary Education Act and Workforce Investment Act Programs

American Indian Teacher and Administrator Corps.—Authorized in Title IX of the Elementary and Secondary Education Act (ESEA) the American Indian Teacher Corps and the American Indian Administrator Corps offer professional development grants designed to increase the number of American Indian teachers and administrators serving their reservation communities. The TCUs request that the Subcommittee maintain funding for these programs at the fiscal year 2010 level.

Adult and Basic Education.—Despite the loss of Federal funding for tribal adult basic education (ABE) in fiscal year 1996, there remains an extremely high demand for ABE programs in the communities that are home to the TCUs. While TCUs continue to offer adult education; GED; remediation and literacy services for American Indians, without dedicated funding these efforts cannot begin to meet demand. The TCUs request that the Subcommittee direct that \$5 million of the funds appropriated each year for the Adult Education State Grants be made available to make competitive awards to TCUs to support the vitally needed reservation-based adult and basic education programs.

DEPARTMENT OF HEALTH AND HUMAN SERVICES PROGRAM

Tribal Colleges and Universities Head Start Partnership Program (DHHS-ACF)

Tribal Colleges and Universities are ideal partners to help achieve the goals of Head Start in Indian Country. The TCUs request that the Subcommittee direct the Head Start Bureau to make available \$5 million, of the more than \$8.1 billion for Head Start included in the President's fiscal year 2012 budget request or of the amount ultimately appropriated in fiscal year 2012, for the TCU-Head Start Partnership program grants. These funds will help to ensure that each of the TCUs has the opportunity to compete for these much-needed partnership funds, thereby giving a jump start to the education successes of more American Indian children growing up in poor and isolated tribal communities.

BACKGROUND ON TRIBAL COLLEGES AND UNIVERSITIES

The Nation's 36 Tribal Colleges and Universities, operating over 75 sites, provide access to quality higher education to 80 percent of Indian Country. TCUs are accredited by independent, regional accreditation agencies and like all institutions of higher education, must undergo stringent performance reviews on a periodic basis to retain their accreditation status. In addition to college level programming, they provide high school completion (GED), basic remediation, job training, college preparatory courses, and adult education and literacy programs. TCUs fulfill additional roles within their respective reservation communities functioning as community centers, libraries, tribal archives, career and business centers, economic development centers, public meeting places, and child and elder care centers. Each TCU is committed to improving the lives of its students through higher education and to moving American Indians toward self-sufficiency.

Tribal Colleges and Universities, chartered by their respective tribal governments, were established in response to the recognition by tribal leaders that local, culturally based institutions are best suited to help American Indians succeed in higher education. TCUs effectively blend traditional teachings with conventional postsecondary curricula. They have developed innovative ways to address the needs of tribal populations and are overcoming long-standing barriers to success in higher education for American Indians. Since the first TCU was established on the Navajo Nation just over 40 years ago, these vital institutions have come to represent the most significant development in the history of American Indian higher education, providing access to, and promoting achievement among, students who may otherwise never have known postsecondary education success.

JUSTIFICATIONS FOR FISCAL YEAR 2012 APPROPRIATIONS REQUESTS FOR TCUS

Tribal colleges and our students are already disproportionately impacted by efforts to reduce the Federal budget deficit and control Federal spending. The final fiscal year 2011 continuing resolution eliminated all of the Department of Housing and Urban Development's MSI community-based programs, including a critical TCU-HUD facilities program. TCUs were able to maximize leveraging potential, often securing even greater non-Federal funding to construct and equip Head Start and early childhood centers; student and community computer laboratories and public libraries; and student and faculty housing in rural and remote communities where few or none of these facilities existed. Important STEM program operated by the National Science Foundation and NASA were cut and for the first time since the program was established in fiscal year 2001, no new TCU-STEM awards, our sole STEM education program, are scheduled to be made in fiscal year 2011. Additionally, TCUs and our students suffer the impact of cuts to programs such as GEAR-UP, TRIO, SEOG, and year-round Pell more profoundly than do mainstream institutions of higher education, which have large endowments, alternative funding sources, including the ability to charge higher tuition rates, enroll more financially stable students, and affluent alumnae. The loss of opportunity that cuts to DoEd, HUD, and NSF programs represent to TCUs, and to other MSIs, is magnified by

cuts to workforce development programs within the Department of Labor, nursing and allied health professions tuition forgiveness and scholarship programs operated by the Department of Health and Human Services, and an important TCU-based nutrition education program planned by USDA. Combined, these cuts strike at the most economically disadvantaged and health-challenged Americans.

Higher Education Act

In 1998, section 316 within Title III–A of the Higher Education Act launched a new program specifically for the Nation’s Tribal Colleges and Universities. Programs under Titles III and V of the Act support institutions that enroll large proportions of financially disadvantaged students and that have low per-student expenditures. TCUs, which are truly developing institutions, are providing access to quality higher education opportunities to some of the most rural, impoverished, and historically underserved areas of the country. Seven of the Nation’s 10 poorest counties are served by TCUs. A stated goal of the Higher Education Act Title III programs is “to improve the academic quality, institutional management and fiscal stability of eligible institutions, in order to increase their self-sufficiency and strengthen their capacity to make a substantial contribution to the higher education resources of the Nation.” The TCU Title III–A program is specifically designed to address the critical, unmet needs of their American Indian students and communities, in order to effectively prepare them to succeed in a global, competitive workforce. Yet, in fiscal year 2011 this critical program was cut by 11 percent. The TCUs urge the Subcommittee to appropriate \$30 million in fiscal year 2012 for HEA Title III–A section 316, which is slightly less than the fiscal year 2010 appropriated funding level and the same as the President’s fiscal year 2012 budget request.

Retention and support services are vital to achieving the national goal of having the highest percentage of college graduates globally, by 2020. The TRIO-Student Support Services program was created out of recognition that college access was not enough to ensure advancement and that multiple factors worked to prevent the successful completion of higher education for many low-income and first-generation students and students with disabilities. Therefore, in addition to maintaining the maximum Pell Grant award level, it is critical that Congress also sustains student assistance programs such as Student Support Services and Upward Bound so that low-income and minority students have the support necessary to allow them to persist in and complete their postsecondary courses of study.

The importance of Pell Grants to TCU students cannot be overstated. U.S. Department of Education figures show that the majority of TCU students receive Pell Grants, primarily because student income levels are so low and our students have far less access to other sources of financial aid than students at State-funded and other mainstream institutions. Within the TCU system, Pell Grants are doing exactly what they were intended to do—they are serving the needs of the lowest income students by helping them gain access to quality higher education, an essential step toward becoming active, productive members of the workforce. The TCUs urge the Subcommittee to continue to fund this critical program at the highest possible level.

Carl D. Perkins Career and Technical Education Act

Tribally Controlled Postsecondary Career and Technical Institutions.—Section 117 of the Carl D. Perkins Career and Technical Education Act provides a competitively awarded grant opportunity for tribally chartered and controlled career and technical institutions. AIHEC requests \$8,200,000 to fund grants under Section 117 of the Perkins Act, the same level included in the President’s fiscal year 2012 budget request.

Native American Career and Technical Education Program.—The Native American Career and Technical Education Program (NACTEP) under Section 116 of the Act reserves 1.25 percent of appropriated funding to support American Indian career and technical programs. The TCUs strongly urge the Subcommittee to continue to support NACTEP, which is vital to the continuation of the career and technical education programs offered at TCUs that provide job training and certifications to remote reservation communities.

Greater Support of Indian Education Programs

American Indian Adult and Basic Education (Office of Vocational and Adult Education).—This program supports adult basic education programs for American Indians offered by State and local education agencies, Indian tribes, agencies, and TCUs. Despite a lack of funding, TCUs must find a way to continue to provide much-in-demand basic adult education classes for those American Indians that the present K–12 Indian education system has failed. Before many individuals can even begin the course work needed to learn a productive skill, they first must earn a

GED or, in some cases, even learn to read. There is an extensive need for basic adult educational programs and TCUs must have adequate and stable funding to provide these essential activities. TCUs request that the Subcommittee direct that \$5 million of the funds appropriated annually for the Adult Education State Grants be made available to make competitive awards to TCUs to help meet the growing demand for adult basic education and remediation program services on their respective reservations.

American Indian Teacher/Administrator Corps (Special Programs for Indian Children).—American Indians are greatly underrepresented in the teaching and school administrator ranks nationally. TCUs are community based institutions of higher education making them ideal catalysts for these two initiatives because of their current work in this area and the existing articulation agreements they hold with 4-year degree granting institutions. The TCUs request that the Subcommittee maintain these two programs at the fiscal year 2010 appropriated levels to continue to produce well-qualified American Indian teachers and school administrators in and for Indian Country.

DEPARTMENT OF HEALTH AND HUMAN SERVICES/ADMINISTRATION FOR CHILDREN AND FAMILIES/HEAD START

Tribal Colleges and Universities (TCU) Head Start Partnership Program.—The TCU-Head Start Partnership has made a lasting investment in our Indian communities by creating and enhancing associate degree programs in Early Childhood Development and related fields. This program has afforded American Indian children Head Start programs of the highest quality. A clear barrier to the ongoing success of this partnership program is the lack of stable funds for the Partnership. The TCUs request that the Subcommittee direct the Head Start Bureau to designate \$5 million, of the more than \$8.1 billion included in the President's fiscal year 2012 budget request for programs under the Head Start Act, be made available for the TCU-Head Start Partnership program.

CONCLUSION

Tribal Colleges and Universities are providing access to high quality higher education opportunities to many thousands of American Indians and essential community services and programs to many more. The modest Federal investment in TCUs has already paid great dividends in terms of employment, education, and economic development and continuation of this solid investment makes sound moral and fiscal sense. TCUs need your help if they are to sustain programs and achieve their missions to serve their students and communities.

Thank you again for this opportunity to present our funding requests. We respectfully ask the Members of the Subcommittee for their continued support of the Nation's Tribal Colleges and Universities and full consideration of our fiscal year 2012 appropriations needs and recommendations.

PREPARED STATEMENT OF THE AMERICAN INSTITUTE FOR MEDICAL AND BIOLOGICAL ENGINEERING

Mister Chairman and Members of the Subcommittee: The American Institute for Medical and Biological Engineering (AIMBE) appreciates the opportunity to submit testimony to advocate for funding for research within the National Institutes of Health (NIH) broadly, and specifically research funding within the National Institute for Biomedical Imaging and Bioengineering (NIBIB). NIH and NIBIB provide avenues for research funding that are vital to the Nation's efforts to support medical and biological engineering (MBE) innovation. AIMBE represents 50,000 individuals and organizations throughout the United States, including major healthcare companies, academic research institutions and the top 2 percent of engineers, scientists and clinicians whose discoveries and innovations have touched the health of nearly every American. While today's testimony focuses on the impact MBE has on improving the health and well-being of Americans, it is important to note that MBE can also have a positive impact on many of the other important issues facing us today; ranging from improvements to the environment by finding green-energy solutions, to solving problems relating to hunger, disease prevention, diagnosis and treatment of disease; to economic growth spurred by the innovation of new health products.

AIMBE was founded in 1991 to establish a clear and comprehensive identity for the field of medical and biological engineering—which applies principles of engineering science and practice to imagine, create, and perfect the medical and biological discoveries that are used to improve the health and quality of life of Americans and

people across the world. AIMBE's vision is to ensure MBE innovations continue to develop for the benefit of humanity.

AIMBE applauds the past support of this committee to provide funding to NIH, and was particularly pleased at the strong investment in NIH provided by the American Recovery and Reinvestment Act. However, we were concerned over recent cuts by the continuing resolution budget for fiscal year 2011. We believe more stable, adequate, and reliable funding is necessary to ultimately ensure America remains competitive and continues to develop innovations that improve human health. An increase in funding will support important work which is highly translatable or applicable research into products that are life-saving, and life enhancing. NIBIB is the only institute at the NIH with the specific purpose of supporting and conducting biomedical engineering research, which impacts all sectors of health across many disease states. Research conducted within NIBIB is on the cutting edge of biomedical engineering and has the potential to save lives and reduce healthcare costs.

While each Institute within the NIH plays a vital role researching and identifying disease prevention and treatment; the NIBIB plays a unique role and has not benefited from large-scale NIH funding increases, such as the doubling of the budget in 2004. First appropriated with its own funding in 2004 (fiscal year 2003 and fiscal year 2004 were funded through transfers from other Institutes within NIH), the mission of NIBIB is to improve health by leading the development and accelerating the application of biomedical technologies. The NIBIB is committed to integrating the physical and engineering sciences with the life sciences to advance basic research and medical care. This is achieved through research and development of new biomedical imaging and bioengineering techniques and devices to fundamentally improve the detection, treatment, and prevention of disease; enhancing existing imaging and bioengineering modalities; supporting related research in the physical and mathematical sciences; encouraging research and development in multidisciplinary areas; supporting studies to assess the effectiveness and outcomes of new biologics, materials, processes, devices, and procedures; developing non-imaging technologies for early disease detection and assessment of health status; and developing advanced imaging and engineering techniques for conducting biomedical research at multiple scales through modeling and simulation. Finally, the NIBIB plays an important role in providing engineering research resources to the entirety of the NIH. As the only engineering research arm within the NIH, NIBIB is often relied upon to partner with other institutes at the NIH to provide engineering expertise. The Laboratory of Molecular Imaging and Nanomedicine, and Laboratory of Bioengineering and Physical Science are two examples of NIBIB's role as a partner for researchers working at other Institutes at the NIH.

We strongly recommend that early-stage, proof-of-concept projects for translational research be funded at an enhanced level, ideally 0.5 percent of all external research budgets, at all Institutes. This is critical to maintaining the U.S. lead in innovation by moving new discoveries and novel systems to the stage where third-party private funding can take them through development to the marketplace where they help patients and the health of Americans. Publicly-held companies cannot invest in this stage of work due to stockholder pressures, so the Federal Government is critical to ensuring the viability of this innovation pipeline.

NIBIB as a Stimulus for Innovation / Cost Effectiveness

Due in large part to the Great Recession, private industry and private investors have been less likely to invest in high-risk research, potentially slowing the pace of innovation. NIBIB fills a void by providing funding for high-risk, high-reward research that leads to the development of new technologies. Often times, private investors in biomedical innovation are unwilling to invest in this type of research, particularly in our current fiscal climate, because of the risks involved. However, NIBIB can be a mechanism to bring new technologies to market and fills the void left by a lack of private capital.

The NIBIB's Quantum Grants program, for example, challenges the research community to propose projects that have a highly focused, collaborative, and interdisciplinary approach to solve a major medical problem or to resolve a highly prevalent technology-based medical challenge. The program consists of a 3-year exploratory phase to assess feasibility and identify best approaches, followed by a second phase of 5 to 7 years. Major advances in medicine leading to quantifiable improvements in public health require the kind of funding commitment and intellectual focus found in the Quantum Grants program at NIBIB, because early stage investors are reluctant to invest in high-risk research. Additionally, the Quantum Grants offer a place for Government to invest in translational research, potentially solving huge medical problems facing Americans today.

The five currently funded Quantum Grants focus on: stem cell therapies for patients suffering from the effects of diabetes and stroke; the utilization of nanoparticles to help visualize brain tumors so that surgeons can easily see and remove a cancerous mass in a patient's brain; the development of an implantable artificial kidney offering an improved quality of life for patients currently undergoing dialysis treatment; and a microchip to capture circulating tumor cells for clinicians to diagnose cancer earlier than ever before, giving patients a greater hope for recovery thanks to earlier detection and treatment. All these projects, in their early stages of funding, have demonstrated promise for improving patient outcomes in the laboratory setting.

An increase of funding to NIBIB and the Quantum Grants program may offer opportunities to expedite research beyond laboratory study and move to clinical trial. For example, if the artificial kidney research is successful and brought to market, the cost to a person with kidney disease would radically decrease because it would eliminate the need for dialysis, which is a expensive, painful, and resource heavy procedure typically done in an out-patient hospital setting.

The Fundamental Role of Engineering Research

Advances in the process of engineering research, in a variety of fields, are a part of technological innovation. Medical and biological engineering draws from research specialties across disciplines (including mechanical, electrical, material, medical and biological engineering, and clinicians), bringing together teams to create unique solutions to the most pressing health problems. Engineering is the practical application of science and math to solve problems. For example, the insulin pump, which is the primary device used by patients with diabetes who requires continuous insulin infusion therapy, is the result of multi-disciplinary effort by engineers to develop a more efficient way to manage diabetes. The science to develop and perfect an insulin pump existed well before the creation of the medical device; however it took biomedical engineers to apply the basic science toward product development.

The first insulin pump to be manufactured was released in the late 70's. It was known as the "big blue brick" because of its size and appearance. It sparked interest among healthcare professionals who saw it as a device that would render syringes obsolete for people who have daily insulin injection needs. While the technology was promising, the first commercial pump lacked the controls and interface to make it a safe alternative to manual injections. Dosage was inaccurate thus making the device more of a danger than a solution.

It was only in the beginning of the 1990's that biomedical engineers began to develop more user-friendly models that could be used by diabetics. Advances in biomedical engineering research focused on reducing device size, increasing energy efficiency (and thus improving battery life), and improving reliability. Such improvements were of great benefit to insulin pump manufacturers who were able to make their models smaller, more affordable, and easier for patients to use. Insulin pumps enable many diabetic patients to live productive lives due to fewer absences from work and reduced hospitalizations.

A similar advancement in the treatment of atherosclerosis through MBE is the use of angioplasty with an arterial stent which releases drugs directly to the coronary artery (referred to as a drug eluting stent). This advancement has replaced more than 500,000 bypass surgeries a year, at an annual cost savings of \$4 billion, and an immeasurable improvement in the quality of life of patients receiving this treatment.

Engineering research in human physiology, specifically in range of motion and function, has increased the function for artificial limbs. The decreasing mortality and increasing number of disabled war veterans highlights the need for more highly functional prosthetics. Engineering research and development processes have taken the strapped wooden leg to a realistic synergic leg and foot transtibial prosthetic that employs advanced biomechanics and microelectronic controls to allow a fuller range of motion, including running. Basic engineering research in polymers and materials science has changed the look and feel of prosthetic limbs so they are no longer easily discernable, reducing the stigma, and making them more durable, lessening the cost of maintenance and replacement. Researchers in Baltimore, Cleveland, and Chicago are developing the next generation of prosthetic limbs, utilizing cutting edge biomedical engineering research to develop prostheses that are more sensitive, more responsive, and more lifelike than anything developed in the past. These new "bionic limbs" are giving patients pieces of their body back, pieces taken from them through traumatic injury or disease. Increases in funding to NIBIB, who uniquely partners with other Federal agencies such as the Department of Veterans Affairs and Department of Defense, may lead to biomedical engineering innovations

to improve the quality of life of warfighters injured on the battlefield as well as civilians.

The engineering research process has played a large part in extending and deploying innovative imaging technologies such as magnetic resonance imaging (MRI) and ultra-fast computed tomography (CT scan). These technologies facilitate early detection of disease and dysfunction, allowing for earlier treatment and slowing the progression of disease. When prescribed correctly these technologies can reduce the costs of healthcare by diagnosing diseases earlier, allowing for earlier clinical intervention and reduced hospitalizations with faster recovery times.

The Nation deserves a strong return on its investment in the basic medical research funded by NIH. Additional engineering research, including translation of basic research into new devices and more efficient medical procedures, is a critical part of ensuring that return. This combination of basic scientific studies and engineering research, will in turn, lead to many technological innovations which will improve the quality of life and well-being of Americans. The Government needs to continue to fund the vital research at NIH and NIBIB to continue to be a leader in healthcare innovation, and for the creation of jobs in the healthcare segment of our national economy.

AIMBE looks forward to the opportunity to continue this dialogue with all of you individually. Thank you again for your time and consideration on this important matter.

PREPARED STATEMENT OF THE AMERICAN LUNG ASSOCIATION

SUMMARY OF PROGRAMS

Centers for Disease Control and Prevention (CDC)

- Increased overall CDC funding—\$7.7 billion
- Funding Healthy Communities—\$52.8 million
- Office on Smoking and Health—\$110 million
- National Asthma Control Program—\$31 million
- Environment and Health Outcome Tracking—\$32.1 million
- Tuberculosis programs—\$231 million
- CDC influenza preparedness—\$160 million
- NIOSH—\$315.3 million
- Prevention and Public Health Fund—\$1 billion, with \$330 million for tobacco control initiatives

National Institutes of Health (NIH)

- Increased overall NIH funding—\$35 billion
- National Heart, Lung and Blood Institute—\$3.514 billion
- National Cancer Institute—\$5.725 billion
- National Institute of Allergy and Infectious Diseases—\$5.395 billion
- National Institute of Environmental Health Sciences—\$779.4 million
- National Institute of Nursing Research—\$163 million
- National Institute on Minority Health & Health Disparities—\$236.9 million
- Fogarty International Center—\$78.4 million

For more information about this testimony, please contact Erika Sward at esward@lungusa.org.

The American Lung Association is pleased to present our recommendations for fiscal year 2012 to the Labor, Health and Human Services, and Education Appropriations Subcommittee. The public health and research programs funded by this committee will prevent lung disease and improve and extend the lives of millions of Americans who suffer from lung disease.

The American Lung Association is the oldest voluntary health organization in the United States, with national offices and local associations around the country. Founded in 1904 to fight tuberculosis, the American Lung Association is the leading organization working to save lives by improving lung health and preventing lung disease through education, advocacy and research.

A Sustained and Sustainable Investment

Mr. Chairman, investments in prevention and wellness can and will pay near term and long term dividends for the health of the American people and people everywhere. That is why the American Lung Association strongly supports the Prevention and Public Health Fund established in the Affordable Care Act. This fund will provide billions of dollars to critical public health initiatives, like community programs that help people quit smoking, support groups for lung cancer patients, and classes that teach people how to avoid asthma attacks.

The United States must also maintain its commitment to medical research. A growing, sustained, predictable and reliable investment in the NIH provides hope for millions afflicted with lung disease. While our focus is on lung disease research, we strongly support increasing the investment in research across the entire National Institutes of Health.

Lung Disease

Each year, almost 400,000 Americans die of lung disease. It is America's number three killer, responsible for one in every six deaths. More than 37 million Americans suffer from a chronic lung disease. Each year lung disease costs the economy an estimated \$173 billion. Lung diseases include: lung cancer, asthma, chronic obstructive pulmonary disease (COPD), tuberculosis, pneumonia, influenza, sleep disordered breathing, pediatric lung disorders, occupational lung disease and sarcoidosis.

Improving Public Health

The American Lung Association strongly supports investments in the public health infrastructure. In order for the Centers for Disease Control and Prevention (CDC) to carry out its prevention mission and to assure an adequate translation of new research into effective State and local programs to improve the health of all Americans, we strongly support increasing the overall CDC funding to \$7.7 billion.

We strongly encourage improved disease surveillance and health tracking to better understand diseases like asthma. We support an appropriations level of \$32.1 million for the Environment and Health Outcome Tracking Network to allow Federal, State and local agencies to track potential relationships between hazards in the environment and chronic disease rates.

We strongly support investments in communities to bring together key stakeholders to identify and improve policies and environmental factors influencing health in order to reduce the burden of chronic diseases. These programs lead to a wide range of improved health outcomes including reduced tobacco use. We strongly recommend at least \$52.8 million in funding for the Healthy Communities program and it remaining a separate, stand alone program.

Tobacco Use

Tobacco use is the leading preventable cause of death in the United States, killing more than 443,000 people every year. Smoking is responsible for one in five U.S. deaths. The direct healthcare and lost productivity costs of tobacco-caused disease and disability are also staggering, an estimated \$193 billion each year.

Given the magnitude of the tobacco-caused disease burden and how much of it can be prevented; the CDC Office on Smoking and Health (OSH) should be much larger and better funded. Historically, Congress has failed to invest in tobacco control—even though public health interventions have been scientifically proven to reduce tobacco use. This neglect cannot continue if the nation wants to prevent disease and promote wellness.

The American Lung Association urges that \$110 million be appropriated to OSH for fiscal year 2012 and that OSH receive an additional one-third, or \$330 million, of funds from the Prevention and Public Health Fund.

Asthma

The American Lung Association strongly opposes the proposal in the President's budget request that would merge the National Asthma Control Program with the Healthy Homes/Lead Poisoning Prevention Program—and then slash the combined programs by more than 50 percent. The Lung Association asks this Committee to retain the National Asthma Control Program as a stand-alone program and that \$31 million be appropriated to it for fiscal year 2012.

It is estimated that almost 25 million Americans currently have asthma, of whom 7.1 million are children. Asthma prevalence rates are over 37 percent higher among African Americans than whites. Studies also suggest that Puerto Ricans have higher asthma prevalence rates and age-adjusted death rates than all other racial and ethnic subgroups. Asthma is the third leading cause of hospitalization among children under the age of 15 and is a leading cause of school absences from chronic disease—accounting for over 10.5 million lost school days in 2008. Asthma costs our healthcare system over \$50.1 billion annually and indirect costs from lost productivity add another \$5.9 billion, for a total of \$56 billion annually.

We recommend that the National Heart, Lung and Blood Institute receive \$3.514 billion and the National Institute of Allergy and Infectious Diseases be appropriated \$5.395 billion, and that both agencies continue their investments in asthma research in pursuit of treatments and cures.

Lung Cancer

An estimated 370,000 Americans are living with lung cancer. During 2010, an estimated 222,520 new cases of lung cancer were diagnosed, and 158,664 Americans died from lung cancer in 2009. Survival rates for lung cancer tend to be much lower than those of most other cancers. African Americans are the most likely to develop and die from lung cancer than persons of any other racial group.

Lung cancer receives far too little attention and focus. Given the magnitude of lung cancer and the enormity of the death toll, the American Lung Association strongly recommends that the NIH and other Federal research programs commit additional resources to lung cancer. We support a funding level of \$5.725 billion for the National Cancer Institute and urge more attention and focus on lung cancer.

Chronic Obstructive Pulmonary Disease

Chronic obstructive pulmonary disease, or COPD, is the third leading cause of death in the United States. It has been estimated that 13.1 million patients have been diagnosed with some form of COPD and as many as 24 million adults may suffer from its consequences. In 2009, 133,737 people in the United States died of COPD. The annual cost to the Nation for COPD in 2010 was projected to be \$49.9 billion. This includes \$29.5 billion in direct healthcare expenditures, \$8.0 billion in indirect morbidity costs and \$12.4 billion in indirect mortality costs. Medicare expenses for COPD beneficiaries were nearly 2.5 times that of the expenditures for all other patients.

The American Lung Association strongly recommends that the NIH and other Federal research programs commit additional resources to COPD research programs. We strongly support funding the National Heart, Lung and Blood Institute and its lifesaving lung disease research program at \$3.514 billion. The American Lung Association also asks the Committee to direct the National Heart, Lung and Blood Institute to work with the CDC and other appropriate agencies to prepare a national action plan to address COPD, which should include public awareness and surveillance activities.

Influenza

Influenza is a highly contagious viral infection and one of the most severe illnesses of the winter season. It is unpredictable, with seasonal death estimates ranging from 3,000 to 49,000 over the last 30 years. Further, the emerging threat of a pandemic influenza is looming as the recently emerging strain of H1N1 reminded us. Public health experts warn that 209,000 Americans could die and 865,000 would be hospitalized if a moderate flu epidemic hits the United States. To prepare for a potential pandemic, the American Lung Association supports funding the Federal CDC Influenza efforts at \$160 million.

Tuberculosis

Tuberculosis primarily affects the lungs but can also affect other parts of the body. There are an estimated 10 million to 15 million Americans who carry latent TB infection. Each has the potential to develop active TB in the future. About 10 percent of these individuals will develop active TB disease at some point in their lives. In 2009, there were 11,545 cases of active TB reported in the United States. While declining overall TB rates are good news, the emergence and spread of multi-drug resistant TB pose a significant threat to the public health of our Nation. Continued support is needed if the United States is going to continue progress toward the elimination of TB. We request that Congress increase funding for tuberculosis programs at CDC to \$231 million for fiscal year 2012.

Conclusion

The American Lung Association also would like to indicate our strong support for CDC and NIH, particularly those programs that impact lung health. We strongly support an across the board increase for NIH with particular emphasis on the National Heart, Lung and Blood Institute, the National Cancer Institute, the National Institute of Allergy and Infectious Diseases, the National Institute of Environmental Health Sciences, the National Institute of Nursing Research, the National Institute on Minority Health & Health Disparities and the Fogarty International Center.

Lung disease is a continuing, growing problem in the United States. It is America's number three killer, responsible for one in six deaths. Progress against lung disease is not keeping pace with other major causes of death and more must be done. The level of support this committee approves for lung disease programs should reflect the urgency illustrated by these numbers.

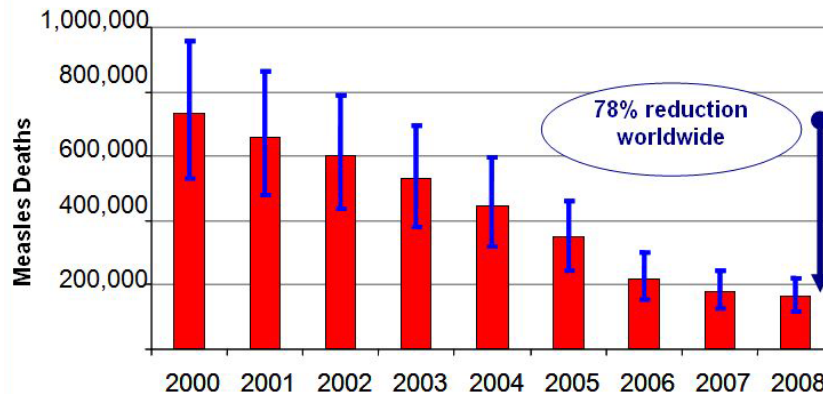
PREPARED STATEMENT OF THE AMERICAN NATIONAL RED CROSS

Chairman Tom Harkin, Ranking Member Richard Shelby, and Members of the Subcommittee, the American Red Cross and the United Nations Foundation appreciate the opportunity to submit testimony in support of measles control activities of the U.S. Centers for Disease Control and Prevention (CDC). The American Red Cross and the United Nations Foundation recognize the leadership that Congress has shown in funding CDC for these essential activities. We sincerely hope that Congress will continue to support the CDC during this critical period in measles control.

In 2001, CDC—along with the American Red Cross, the United Nations Foundation, the World Health Organization, and UNICEF—founded the Measles Initiative, a partnership committed to reducing measles deaths globally. The current U.N. goal is to reduce measles deaths by 95 percent by 2015 compared to 2000 estimates. The Measles Initiative is committed to reaching this goal by providing technical and financial support to governments and communities worldwide.

The Measles Initiative has achieved “spectacular”¹ results by supporting the vaccination of more than 700 million children. Largely due to the Measles Initiative, global measles mortality dropped 78 percent, from an estimated 733,000 deaths in 2000 to 164,000 in 2008 (the latest year for which data is available). During this same period, measles deaths in Africa fell by 92 percent, from 371,000 to 28,000.

Figure 1: Estimated Number of Global Measles Deaths, 2000-2008



Working closely with host governments, the Measles Initiative has been the main international supporter of mass measles immunization campaigns since 2001. The Initiative mobilized more than \$700 million and provided technical support in more than 60 developing countries on vaccination campaigns, surveillance and improving routine immunization services. From 2000 to 2008, an estimated 4.3 million measles deaths were averted as a result of these accelerated measles control activities at a donor cost of \$184/death averted, making measles mortality reduction one of the most cost-effective public health interventions.

Nearly all the measles vaccination campaigns have been able to reach more than 90 percent of their target populations. Countries recognize the opportunity that measles vaccination campaigns provide in accessing mothers and young children, and “integrating” the campaigns with other life-saving health interventions has become the norm. In addition to measles vaccine, Vitamin A (crucial for preventing blindness in under nourished children), de-worming medicine (reduces malnutrition), and insecticide-treated bed nets (ITNs) for malaria prevention are distributed during vaccination campaigns. The scale of these distributions is immense. For example, more than 40 million ITNs were distributed in vaccination campaigns in the last few years. The delivery of multiple child health interventions during a single campaign is far less expensive than delivering the interventions separately, and this strategy increases the potential positive impact on children’s health from a single campaign.

¹The Lancet, Volume 8, page 13 (January 2008).

The extraordinary reduction in global measles deaths contributed nearly 25 percent of the progress to date toward Millennium Development Goal #4 (reducing under-five child mortality). However, since 2009, Africa has experienced outbreaks affecting 28 countries, resulting in a four-fold increase in reported measles cases. These outbreaks highlight the fragility of the last decade's progress. If mass immunization campaigns are not continued, measles deaths will increase rapidly with more than half a million deaths estimated for 2013 alone.

To achieve the 2015 goal and avoid a resurgence of measles the following actions are required:

- Fully implementing activities, both campaigns and strengthening routine measles coverage, in India since it is the greatest contributor to the global burden of measles.
- Sustaining the gains in reduced measles deaths, especially in Africa, by strengthening immunization programs to ensure that more than 90 percent of infants are vaccinated against measles through routine health services before their first birthday as well as conducting timely, high quality mass immunization campaigns.
- Securing sufficient funding for measles-control activities both globally and nationally. The Measles Initiative faces a funding shortfall of an estimated \$212 million for 2012–2015. Implementation of timely measles campaigns is increasingly dependent upon countries funding these activities locally. The decrease in donor funds available at global level to support measles elimination activities makes increased political commitment and country ownership of the activities critical for achieving and sustaining the goal of reducing measles mortality by 90 percent.

If these challenges are not addressed, the remarkable gains made since 2000 will be lost and a major resurgence in measles deaths will occur.

By controlling measles cases in other countries, U.S. children are also being protected from the disease. Measles can cause severe complications and death. A resurgence of measles occurred in the United States between 1989 and 1991, with more than 55,000 cases reported. This resurgence was particularly severe, accounting for more than 11,000 hospitalizations and 123 deaths. Since then, measles control measures in the United States have been strengthened and endemic transmission of measles cases have been eliminated here since 2000. However, importations of measles cases into this country continue to occur each year. The costs of these cases and outbreaks are substantial, both in terms of the costs to public health departments and in terms of productivity losses among people with measles and parents of sick children. For example in 2008, 2 hospitals in Arizona spent an estimated \$800,000 responding and containing 7 measles cases.² The United States is currently on track to have more measles cases in 2011 than any year in more than a decade.

The Role of CDC in Global Measles Mortality Reduction

Since fiscal year 2001, Congress has provided approximately \$43.6 million annually in funding to CDC for global measles control activities. These funds were used toward the purchase of measles vaccine for use in large-scale measles vaccination campaigns in more than 60 countries in Africa and Asia, and for the provision of technical support to Ministries of Health. Specifically, this technical support includes: Planning, monitoring, and evaluating large-scale measles vaccination campaigns; conducting epidemiological investigations and laboratory surveillance of measles outbreaks; and conducting operations research to guide cost-effective and high quality measles control programs.

In addition, CDC epidemiologists and public health specialists have worked closely with WHO, UNICEF, the United Nations Foundation, and the American Red Cross to strengthen measles control programs at global and regional levels. While it is not possible to precisely quantify the impact of CDC's financial and technical support to the Measles Initiative, there is no doubt that CDC's support—made possible by the funding appropriated by Congress—was essential in helping achieve the sharp reduction in measles deaths in just 8 years.

The American Red Cross and the United Nations Foundation would like to acknowledge the leadership and work provided by CDC and recognize that CDC brings much more to the table than just financial resources. The Measles Initiative is fortunate in having a partner that provides critical personnel and technical support for vaccination campaigns and in response to disease outbreaks. CDC personnel have routinely demonstrated their ability to work well with other organizations and

²Chen SY, Anderson S, Kutty PK, et al. *J of Infect Dis* 2011; 203: 1517–1525.

provide solutions to complex problems that help critical work get done faster and more efficiently.

In fiscal year 2011, Congress appropriated approximately \$49 million to fund CDC for global measles control activities, this represented at \$2.6 million decrease from the previous year. The American Red Cross and the United Nations Foundation respectfully request a return to fiscal year 2010 funding levels (\$52 million) for fiscal year 2012 for CDC's measles control activities to protect the investment of the last decade, and prevent a global resurgence of measles and a loss of progress toward Millennium Development Goal #4.

Your commitment has brought us unprecedented victories in reducing measles mortality around the world. In addition, your continued support for this initiative helps prevent children from suffering from this preventable disease both abroad and in the United States.

Thank you for the opportunity to submit testimony.

PREPARED STATEMENT OF THE AMERICAN NURSES ASSOCIATION

The American Nurses Association (ANA) appreciates the opportunity to comment on fiscal year 2012 appropriations for the Title VIII Nursing Workforce Development Programs and Nurse-Managed Health Clinics. Founded in 1896, ANA is the only full-service professional association representing the interests of the Nation's 3.1 million registered nurses (RNs) through its State nurses associations, and organizational affiliates. The ANA advances the nursing profession by fostering high standards of nursing practice, promoting the rights of nurses in the workplace, and projecting a positive and realistic view of nursing.

As the largest single group of clinical healthcare professionals within the health system, licensed registered nurses are educated and practice within a holistic framework that views the individual, family and community as an interconnected system that can keep us well and help us heal. Registered nurses are fundamental to the critical shift needed in health services delivery, with the goal of transforming the current "sick care" system into a true "healthcare" system. RNs are the backbone of hospitals, community clinics, school health programs, home health and long-term care programs, and serve patients in many other roles and settings. The ANA gratefully acknowledges this Subcommittee's history of support for nursing education. We also appreciate your continued recognition of the important role nurses play in the delivery of quality healthcare services, including Nurse-Managed Health Clinics (NMHCs).

The Nursing Shortage

A sufficient supply of nurses is critical in providing our Nation's population with quality healthcare. Registered Nurses (RNs) and Advanced Practice Registered Nurses (APRNs) play an integral role in the delivery of primary care and help to bring the focus of our healthcare system back where it belongs—on the patient and the community. The current U.S. nursing shortage is already having a detrimental impact on our healthcare system, and it is expected to grow to a 260,000 nurse shortfall by 2025. A shortage of this magnitude would be twice as large as any shortage experienced by this country since the 1960s. Cuts to Title VIII funding would be detrimental to the healthcare system and the patients we serve.

As noted above, the nursing shortage is having a detrimental impact on the entire healthcare system. Numerous studies have shown that nursing shortages contribute to medical errors, poor patient outcomes, and increased mortality rates. A study published in the March 17, 2011 issue of the *New England Journal of Medicine* shows that inadequate staffing is tied to higher patient mortality rate. The study supports findings of previous studies and finds that higher than typical rates of patient admissions, discharges, and transfers during a shift were associated with increased mortality—an indication of the important time and attention needed by RNs to ensure effective coordination of care for patients at critical transition periods.

Nursing Workforce Development Programs

The Nursing Workforce Development programs, authorized under Title VIII of the Public Health Service Act (42 U.S.C. 296 et seq.) support the supply and distribution of qualified nurses to meet our Nation's healthcare needs. Over the last 46 years, Title VIII programs have addressed each aspect of the nursing shortages—education, practice, retention, and recruitment.

—Title VIII provides the largest source of Federal funding for nursing education, offering financial support for nursing education programs, individual students, and nurses.

- These programs bolster nursing education at all levels, from entry-level preparation through graduate study.
- Title VIII programs favor institutions that educate nurses for practice in rural and medically underserved communities.
- In fiscal year 2008, these programs provided loans, scholarships, traineeships, and programmatic support to 77,395 nursing students and nurses.

The 107th Congress recognized the detrimental impact of the developing nursing shortage and passed the Nurse Reinvestment Act (Public Law 107–205). This law improved the Title VIII Nursing Workforce Development programs to meet the unique characteristics of today's shortage. These programs were also strengthened and reauthorized with the adoption of the Affordable Care Act. This achievement holds the promise of recruiting new nurses into the profession, promoting career advancement within nursing and improving patient care delivery. However, this promise cannot be met without a significant investment. ANA strongly urges Congress to increase funding for Title VIII programs to a total of \$313.075 million in fiscal year 2012. This is also the amount requested in President Obama's fiscal year 2012 budget.

Current funding levels are clearly failing to meet the need. In fiscal year 2008 (most recent year statistics are available), the Health Resources and Services Administration (HRSA) was forced to turn away 92.8 percent of the eligible applicants for the Nurse Education Loan Repayment Program (NELRP), and 53 percent of the eligible applicants for the Nursing Scholarship program due to a lack of adequate funding. These programs are used to direct RNs into areas with the greatest need—including departments of public health, community health centers, and disproportionate share hospitals.

Title VIII includes the following program areas:

Nursing Education Loan Repayment Program and Scholarships.—This line item is comprised of the Nurse Education Loan Repayment Program (NELRP) and the Nursing Scholarship Program (NSP). In fiscal year 2010, the Nurse Education Loan Repayment Program and Scholarships received \$93.8 million.

The NELRP repays up to 85 percent of a RN's student loans in return for full-time practice in a facility with a critical nursing shortage. The NELRP nurse is required to work for at least 2 years in a designated facility, during which time the NELRP repays 60 percent of the RN's student loan balance. If the nurse applies and is accepted for an optional third year an additional 25 percent of the loan is repaid.

In fiscal year 2008, HRSA received 3,039 applications for the nursing scholarship. Due to lack of funding, a mere 177 scholarships were awarded. Therefore, 2,862 nursing students (94 percent) willing to work in facilities with a critical shortage were denied access to this program.

Nurse Faculty Loan Program.—This program establishes a loan repayment fund within schools of nursing to increase the number of qualified nurse faculty. Nurses may use these funds to pursue a master's or doctoral degree. They must agree to teach at a school of nursing in exchange for cancellation of up to 85 percent of their educational loans, plus interest, over a 4-year period. In fiscal year 2010, this program received \$25 million.

This program is vital given the critical shortage of nursing faculty. America's schools of nursing cannot increase their capacity without an influx of new teaching staff. Last year, schools of nursing were forced to turn away tens of thousands of qualified applicants due largely to the lack of faculty. In fiscal year 2008, HRSA funded 95 faculty loans.

Nurse Education, Practice, and Retention Grants.—This section is comprised of many programs designed to support entry-level nursing education and to enhance nursing practice. The education grants are designed to expand enrollments in baccalaureate nursing programs, develop internship and residency programs to enhance mentoring and specialty training, and provide new technologies in education including distance learning. All together, the Nurse Education, Practice, and Retention Grants supported 42,761 nurses and nursing students in fiscal year 2008. The program received \$39.8 million in fiscal year 2010.

Nursing Workforce Diversity.—This program provides funds to enhance diversity in nursing education and practice. It supports projects to increase nursing education opportunities for individuals from disadvantaged backgrounds—including racial and ethnic minorities, as well as individuals who are economically disadvantaged. In fiscal year 2008, 85 applications were received for workforce diversity grants, 51 programs were funded. In fiscal year 2010, these programs received \$16 million.

Advanced Nursing Education.—Advanced practice registered nurses (APRNs) are nurses who have attained advanced expertise in the clinical management of health conditions. Typically, an APRN holds a master's degree with advanced didactic and clinical preparation beyond that of the RN. Most have practice experience as RNs

prior to entering graduate school. Practice areas include, but are not limited to: anesthesiology, family medicine, gerontology, pediatrics, psychiatry, midwifery, neonatology, and women's and adult health. Title VIII grants have supported the development of virtually all initial State and regional outreach models using distance learning methodologies to provide advanced study opportunities for nurses in rural and remote areas. In fiscal year 2009, 5,649 advanced education nurses were supported through these programs. In fiscal year 2010, these programs received \$64.4 million.

Comprehensive Geriatric Education Grants.—This authority awards grants to train and educate nurses in providing healthcare to the elderly. Funds are used to train individuals who provide direct care for the elderly, to develop and disseminate geriatric nursing curriculum, to train faculty members in geriatrics, and to provide continuing education to nurses who provide geriatric care. In fiscal year 2008, 6,514 nurses and nursing students were supported through these programs. In fiscal year 2010, these grants received \$4.5 million. The growing number of elderly Americans and the impending healthcare needs of the baby boom generation make this program critically important.

Nurse-Managed Health Clinics

A healthcare system must value primary care and prevention to achieve improved health status of individuals, families and the community. As Congress recognized through the passage of the Affordable Care Act (ACA) money, resources and attention must be reallocated in the health system to highlight importance of, and create incentives for, primary care and prevention.

Nurses are strong supporters of community and home-based models of care. We believe that the foundation for a wellness-based healthcare system is built in these settings and reduces the amount of both money and human suffering. ANA supports the renewed focus on new and existing community-based programs such as Nurse Managed Health Centers (NMHCs).

Currently, there are more than 200 Nurse Managed Health Centers (NMHCs) in the United States which have provided care to over 2 million patients annually. ANA believes that Nurse Managed Health Centers (NMHCs) are an efficient, sensible, cost-effective way to deliver primary healthcare services. These clinics are also used as clinical sites for nursing education. The nurse-managed care model is especially effective in disease prevention and early detection, management of chronic conditions, treatment of acute illnesses, health promotion, and more. Nurse Managed Health Centers (NMHCs) can also provide a medical home for underserved individuals as well as partnering with the Federal Government to reduce health disparities.

ANA was pleased to see that the Affordable Care Act (ACA) provided grant eligibility to Nurse-Managed Health Clinics (NMHCs) to support operating costs. ACA also authorized up to \$50 million a year to support operating costs. ANA strongly urges Congress to provide \$20 million for the Nurse-Managed Health Clinics authorized under Title VIII of the Public Health Service Act in fiscal year 2012 as recommended in President Obama's fiscal year 2012 budget.

Conclusion

While ANA appreciates the continued support of this Subcommittee, we are concerned that Title VIII funding levels have not been sufficient to address the growing nursing shortage. In preparation for the implementation of healthcare reform initiatives, which ANA supports, we believe there will be an even greater need for nurses and adequate funding for these programs is even more essential. Registered Nurses (RNs) and Advanced Practice Nurses (APRNs) are key providers whose care is linked directly to the availability, cost, and quality of healthcare services. ANA asks you to meet today's shortage with a relatively modest investment of \$313.075 million in fiscal year 2012 for the Health Resources and Services Administration Nursing Workforce Development programs and \$20 million for Nurse-Managed Health Clinics. Thank you.

PREPARED STATEMENT OF THE AMERICAN PHYSICAL THERAPY ASSOCIATION

On behalf of more than 77,000 physical therapists, physical therapist assistants, and students of physical therapy, the American Physical Therapy Association (APTA) thanks you for the opportunity to submit official testimony regarding recommendations for the fiscal year 2012 appropriations. APTA's mission is to improve the health and quality of life of individuals in society by advancing physical therapist practice, education, and research. Physical therapists across the country utilize a wide variety of federally funded resources to work collaboratively toward the ad-

vancement of these goals. APTA's recommendations for Federal funding, as outlined in this document, reflect a commitment toward these priorities for the good of society and the rehabilitation community.

Department of Health and Human Services

National Institutes of Health (NIH)

Rehabilitation research was funded at \$458 million within NIH's approximately \$31.2 billion budget in fiscal year 2010. This represents roughly 1 percent of NIH funds for an area of biomedical research that impacts a growing percentage of our Nation's seniors, persons with disabilities, young persons with chronic disease or traumatic injuries, and children with development disabilities. The Institute of Medicine (IOM) estimates that 1 in 7 individuals have an impairment or limitation that significantly limits their ability to perform activities of daily living. Investment in and recognition of rehabilitation within NIH is a necessary step toward continuing to meet the needs of these individuals in our population. Through the American Recovery and Reinvestment Act (ARRA), rehabilitation research was able to take advantage of an extra infusion of approximately \$75 million in fiscal year 2009 and \$93 million in fiscal year 2010. However, APTA believes that rehabilitation research at NIH has been under-funded for many years. The funds currently utilized are well-invested for the impact that rehabilitation interventions will have on the quality of lives of individuals. Continued investment and greater recognition and coordination of rehabilitation research among Institutes and across Federal departments will enhance the returns the Federal Government receives when investing in this area. Taking this into consideration, APTA recommends \$31.829 billion (a \$629 million increase over fiscal year 2010) for NIH in fiscal year 2012 to ensure that the momentum is maintained that was gained under the ARRA investment to improve health, spur economic growth and innovation, and advance science. APTA recognizes the extraordinary circumstances that exist during these tough budgetary times, however it still remains crucial that Federal investments in healthcare research are preserved and at least kept on pace with the rate of inflation.

Specifically, the physical therapy and rehabilitation science community recommends that Congress allocate crucial funding enhancements in the following institutes:

- \$1.356 billion (a 2 percent increase over fiscal year 2010) for the Eunice Kennedy Shriver National Institute of Child Health and Human Development (NICHD) which houses the National Center for Medical Rehabilitation Research (NCMRR), the only entity within NIH explicitly focused on the advancement of rehabilitation science. NCMRR fosters the development of scientific knowledge needed to enhance the health, productivity, independence, and quality-of-life of people with disabilities. A primary goal of the Center-supported research is to bring the health-related problems of people with disabilities to the attention of the best scientists in order to capitalize upon the myriad advances occurring in the biological, behavioral, and engineering sciences.
- \$1.66 billion (a 2 percent increase over fiscal year 2010) for the National Institute of Neurological Disorders and Stroke (NINDS). This funding level is required to enhance existing initiatives and invest in new and promising research to prevent stroke and advance rehabilitation in stroke treatment. Despite being a major cause of disability and the number three cause of death in the United States, NIH invests only 1 percent of its budget in stroke research. However, APTA recognizes the advancements that NIH-funded research has achieved in the specific area of stroke rehabilitation. APTA commends this area of leadership at NIH and encourages a continued focus on rehabilitation interventions and physical therapy to maximize an individual's function and quality of life after a stroke.
- \$550 million for the National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS) for arthritis and musculoskeletal research.

Centers for Disease Control and Prevention (CDC)

APTA was disappointed to see the cuts that have been implemented within CDC for fiscal year 2011. The contributions of CDC to the lives of countless individuals are limited only by the resources available for carrying out its vital mission. Our Nation and the world will continue to benefit from further improvement in public health and investment in scientific advancement and prevention. APTA recommends Congress provide at least \$7.7 billion for CDC's fiscal year 2012 "core programs" in the fiscal year 2012 Labor-HHS-Education Appropriations bill. This request reflects the support CDC will need to fulfill its core missions for fiscal year 2012. APTA strongly believes that the activities and programs supported by CDC are essential in protecting the health of the American people. APTA supports the Prevention and

Public Health Fund (PPHF) and its underlying purpose of providing supplemental funding as an investment to expand infrastructure for prevention initiatives. We are not supportive of efforts to use the PPHF to supplant current programmatic funding within the budgets of agencies, such as CDC.

Physical therapists play an integral role in the prevention, education, and assessment of the risk for falls. The CDC is currently only allocating \$2 million per year to address the increasing prevalence of falls, a problem costing more than \$19.2 billion a year. Among older adults, falls are the leading cause of injury deaths. This is why APTA respectfully requests that \$21.7 million be provided in funding for the “Unintentional Injury Prevention” account to allow CDC’s National Center for Injury Prevention and Control (NCIPC) to comprehensively address the large-scale growth of older adult falls. CDC has made great strides in developing and laying the groundwork for evidence-based falls prevention programs that link clinical intervention with community-based programs to make an impactful benefit for American society in addressing this expensive and burdensome healthcare problem. Without an increase in resources, CDC is unable to effectively scale-up and expand infrastructure beyond the few cities in which the programs have currently been developed to begin reaching all communities across the United States.

Traumatic Brain Injury (TBI) is a leading cause of death and disability among young Americans and continues to be the signature injury of the conflicts in Iraq and Afghanistan. CDC estimates that at least 5.3 million Americans, approximately 2 percent of the U.S. population, currently require lifelong assistance to perform activities of daily living as a result of TBI. High quality, evidence-based rehabilitation for TBI is typically a long and intensive process. From the battlefield to the football field, American adults and youth continue to sustain TBIs at an alarming rate and funding is desperately needed for better diagnostics and evaluation, treatment guidelines, improved quality of care, education and awareness, referral services, State program services, and protection and advocacy for those less able to advocate for themselves. APTA recommends at least \$10 million in fiscal year 2012 for CDC’s TBI Registries and Surveillance, Brain Injury Acute Care Guidelines, Prevention, and National Public Education/Awareness programs, specifically with the great work that has been produced through the “Heads Up” concussions initiative.

CDC’s Well-Integrated Screening and Evaluation for Women Across the Nation (WISEWOMAN) programs screens uninsured and under-insured low-income women ages 40 to 64 for heart disease and stroke risk and those with abnormal results receive counseling, education, referral and follow up. WISEWOMAN reached over 70,000 women in only 20 States from July 2008 to June 2010. Of these women, nearly 90 percent were found to have one or more heart disease or stroke risk factors and about 30 percent had at least three. More than 60 percent of the women participated in a minimum of one behavioral modification session, and among those WISEWOMAN participants who were re-screened one year later, average blood pressure and cholesterol levels had decreased considerably. APTA recommends \$37 million (\$16.3 million increase over fiscal year 2010) for CDC’s WISEWOMAN Program in fiscal year 2012.

Health Resources and Services Administration (HRSA)

With the passage of healthcare reform legislation, it becomes more important now than ever that America is able to supply an adequate and well-trained healthcare workforce to meet the demands of an expanded market of U.S. citizens that have health insurance coverage. APTA urges you to provide at least \$7.65 billion for HRSA in fiscal year 2012. While we recognize the reality of the current fiscal climate, this amount reflects the minimum amount necessary for the agency to adequately meet the needs of the populations it serves. The relatively level funding HRSA has received over the past several years has undermined the ability of its successful programs to grow and be expanded to represent professions that shape the entire healthcare team, such as physical therapy. Any shortage areas of physical therapists and rehabilitation professionals may become more accentuated as the percentage of the U.S. population that has health coverage increases and demand rises. It is crucial that efforts are undertaken to strengthen the healthcare workforce and delivery across the whole spectrum of an individual’s care—from onset through rehabilitation. More resources are needed for HRSA to achieve its ultimate mission of ensuring access to culturally competent, quality health services; eliminating health disparities; and rebuilding the public health and healthcare infrastructure.

In conjunction with the importance of funding TBI efforts within CDC, APTA also recommends \$8 million for the HRSA Federal TBI State Grant Program and \$4 million for the HRSA Federal TBI Protection & Advocacy (P&A) Systems Grant Program.

Department of Education

In 2008, as part of the reauthorization of the Higher Education Act (Public Law 110-315), the Loan Forgiveness for Service in Areas of National Need (LFSANN) program was created. This program would provide a modest amount of loan forgiveness for a variety of education and healthcare professional groups, including physical therapists, upon a commitment to serve in targeted populations that were identified as areas of crucial importance and national need. However, the program has not been implemented because it has not received any funding. APTA commends the recent efforts of Congress to reform the higher education loan industry. The lowering of the limit on the income-based repayment plan for consolidated Federal Direct Loans will assist the burdensome payments for all higher education loan borrowers. However, this program still fails to meet the most important impact of LFSANN—channeling providers and professionals into areas where there are demonstrated shortages and high need, such as physical therapy care for veterans and children and adolescents. APTA strongly urges Congress to take action and provide \$10 million in initial funding for this vital LFSANN program that will impact the healthcare and education services of those most in need.

National Institute for Disability and Rehabilitation Research (NIDRR)

NIDRR has been one of the longest standing agencies to focus on federally funded medical rehabilitation research. Rehabilitation research makes a difference in the lives of individuals with impairments, functional limitations, and disability. Advancements in rehabilitation research have led to greater quality of life for individuals who have spinal cord injuries, loss of limb, stroke and other orthopedic, neurological, and cardiopulmonary disorders. Investment in NIDRR is a necessary step toward continuing to meet the needs of individuals in our population who have chronic disease, developmental disabilities or traumatic injuries. Therefore, APTA recommends at least \$20 million per year for NIDRR to support research and development, capacity building, and knowledge translation in health, rehabilitation, and function.

APTA also requests \$11 million for NIDRR's TBI Model Systems administered by the Department of Education. The TBI Model Systems of Care program represents an already existing vital national network of expertise and research in the field of TBI, and weakening this program would have resounding effects on both military and civilian populations. The TBI Model Systems are the only source of non-proprietary longitudinal data on what happens to people with brain injury. They are a key source of evidence-based medicine and rehabilitation care for this crucial and growing population.

Conclusion

As previously stated, APTA recognizes the extraordinarily tough budgetary pressures that are facing the U.S. Federal Government. However, there are certain programs and agencies that are essential and vital to the health of Americans. APTA looks forward to working with the Subcommittee and the various agencies outlined above to advance the capability of meeting the rehabilitation needs of society. If the Subcommittee has questions or needs additional resources, please contact Nate Thomas, Associate Director of Federal Government Affairs at APTA, at natethomas@apta.org or 703-706-8527. APTA's mailing address is provided on the letterhead of the first page of this document.

PREPARED STATEMENT OF THE AMERICAN PSYCHOLOGICAL ASSOCIATION

This statement is the testimony of the American Psychological Association (APA), the largest scientific and professional organization representing psychology in the United States and the world's largest association of psychologists. APA's membership includes more than 154,000 researchers, educators, clinicians, consultants and students. Through its divisions in 54 subfields of psychology and affiliations with 60 State, territorial and Canadian provincial associations, APA works to advance psychology as a science, as a profession and as a means of promoting health, education and human welfare. APA welcomes the opportunity to bring to your attention some priority requests and concerns for the fiscal year 2012 appropriations bill.

Health Resources and Services Administration

Bureau of Health Professions

The APA requests that the Subcommittee include \$5 million for the Graduate Psychology Education Program (GPE) within the Health Resources and Services Administration. This nationally competitive grant program provides integrated healthcare

services to underserved rural and urban communities and individuals with the least access to much needed mental and behavioral health services and support (e.g., children, older adults, and chronically ill persons, victims of abuse or trauma, including veterans). To date there have been over 100 grants in 32 States to universities and hospitals throughout the Nation. All psychology graduate students who benefited from GPE funds are expected to work with underserved populations and over 80 percent will work in underserved areas immediately after completing the training.

Currently GPE is authorized under the Public Health Service Act [Public Law 105–392 Section 755(b)(1)(J)] and funded under the “Allied Health and Other Disciplines” account in the Labor-HHS Appropriations Bill. An authorization of Appropriations of \$10 million was included in the Patient Protection and Affordable Care Act. It was also included in the fiscal year 2011 Omnibus bill, which did not pass, for \$7 million; and it has been included in H.R. 1 for fiscal year 2011 and the Senate 2011 continuing resolutions, as well as the President’s budget (for a number of years). Established in 2002, GPE grants have supported the interdisciplinary training of over 3,000 graduate students of psychology and other health professions to provide integrated healthcare services to underserved populations. The fiscal year 2012 GPE funding request will focus especially on providing services to returning military personnel and their families, unemployed persons and older adults in underserved communities. Also the GPE funding request will also be used to create training opportunities at our Nation’s federally Qualified Health Centers, which play a critical role in meeting the healthcare needs of our Nation’s underserved persons.

National Institutes of Health (NIH)

As a member of the Ad hoc Group for Medical Research Funding and the Coalition for Health Funding, APA encourages the Subcommittee to provide a minimum of \$31.8 billion for the NIH. Sustained growth for NIH will build on the Nation’s longstanding, bipartisan commitment to better health, which has established the United States as the world leader in medical research and innovation. NIH research means hope for patients. Potentially revolutionary new avenues of research hold promise for new early screenings and new treatments for disease. Recent funding has created dramatic new research opportunities in areas ranging from genetics to the behavioral research conducted by APA members. In addition, NIH research is boosting the economies of communities nationwide, at over 3,000 universities, medical schools, teaching hospitals and other research institutions. This committee should take justifiable pride in the progress and promise that NIH research is engendering.

There are several issues at NIH to which APA would draw the Subcommittee’s attention:

—*Addictions Research Institute.*—NIH research on alcohol and substance abuse has shed important light on critical policy issues ranging from the rehabilitation of drug-addicted felons to treatment of children exposed to substances in utero. APA is closely monitoring NIH’s proposal to create a new combined institute that would fund research on both alcohol and substance abuse. In our view this research is significantly underfunded when weighed against the public health and public safety impacts of alcohol, tobacco and illicit substance use, and we are concerned that research funding be maintained and increased as the new institute is created. We urge the Subcommittee to insist that NIH establish rigorous and transparent baselines of current funding levels and the allocation of those funds across the existing NIH Institutes and Centers to better assess and understand the proposed organizational change. The continued active involvement of extramural scientists at every stage of this process, as well as that of the Office of Behavioral and Social Sciences Research, will help ensure that the new institute has the right infrastructure to truly optimize the conduct of addiction research.

—*Funding for OppNet.*—For fiscal year 2012, APA supports a budget of \$38.2 million for OBSSR. This sum reflects the Administration’s request of \$28 million for OBSSR and includes \$10 million needed to support the NIH-wide commitment to carry out OppNet, an initiative strongly supported by the Subcommittee. The OppNet initiative has made significant progress since its start. Thus far, OppNet has awarded 35 competitive revisions to add basic science projects to existing research project grants. Eight competitive revisions to Small Business Innovation Research/Small Business Technology and Transfer projects have been awarded. OppNet has also provided much-needed training in basic social and behavioral sciences research.

—*National Center to Advance Translational Sciences.*—APA believes firmly that the proposed new National Center to Advance Translational Sciences should in-

clude sufficient staff expertise and resources to manage research on the translation of behavioral interventions into communities. Just as it is critical for NIH to speed the translation of research into drug or technology development, it is critical for behavioral interventions on diet, exercise, and psychotherapy to be translated and disseminated to communities in need of them.

Centers for Disease Control and Prevention

As a member of the Centers for Disease Control and Prevention (CDC) Coalition, APA supports an appropriation of \$7.7 billion for CDC's "core programs" for fiscal year 2012. In addition to playing a key role in maintaining a strong public health infrastructure and protecting Americans from public health threats and emergencies, CDC programs play a crucial role in reducing healthcare costs and strengthening the Nation's health system. This request reflects the minimum amount CDC will need to fulfill its core missions for fiscal year 2012.

National Center for Health Statistics.—APA endorses the President's fiscal year 2012 request of \$162 million in funding for NCHS. NCHS is the Nation's principal health statistics agency, and the health data collected by NCHS are an essential part of the Nation's statistical and public health infrastructure. The Subcommittee's support is helping NCHS rebuild after years of underinvestment and restore the collection of essential health data. With your continued support, NCHS will modernize its data collection efforts to produce higher quality, more timely data.

Prevention Research Centers.—APA recognizes the importance of a focus on prevention in improving health in America and the significant contributions of the Prevention Research Centers network of community, academic, and public health partners to research on evidenced based approaches in health promotion. APA urges Congress to allocate the resources necessary to support the Prevention Research Centers so that this network of academic institutions and organizations can continue to contribute as widely and effectively to prevention science. APA opposes any program consolidation that would lead to disproportionate funding cuts for the Prevention Research Centers. Insofar as consolidation of programs as proposed in the fiscal year 2012 President's budget occurs, APA requests that Congress designate specific funding for Prevention Research Centers.

Substance Abuse and Mental Health Services Administration (SAMHSA)

APA is highlighting three requests for the Committee's support at SAMHSA's Center for Mental Health Services:

- First, APA strongly recommends that Congress allocate the fully authorized amount (\$50 million) for SAMHSA's National Child Traumatic Stress Network (NCTSN) program which works to aid the recovery of children, families, and communities impacted by a wide range of trauma, including physical and sexual abuse, natural disasters, sudden death of a loved one, the impact of war on military families, and much more. Specifically, APA recommends that SAMHSA increase the number of NCTSN grantees and maintain the collaborative model envisioned in the original authorization.
- Second, APA urges the Committee to increase its support for the Minority Fellowship Program. Racial and ethnic minorities are projected to represent 40 percent of our Nation's population in upcoming years. Therefore, APA urges Congress to increase funding for the Minority Fellowship Program by \$2.6 million. This unique workforce development initiative trains ethnic minority healthcare professionals to bring mental and behavioral healthcare services to rural and underserved minority communities.
- Third, APA encourages Congress to provide at least level support for the three programs authorized under the Garrett Lee Smith Memorial Act, especially the Campus Suicide Prevention Program. These programs make suicide prevention initiatives and mental health support available to populations in need and merit continued appropriations.

Administration on Aging

Mental health.—Older adults are one of the fastest growing segments of the U.S. population and approximately 25 percent of older Americans have a mental or behavioral health problem. In particular, older white males (age 85 and over) currently have the highest rates of suicide of any group in the United States. Accordingly, APA urges an expanded effort to address the mental and behavioral health needs of older adults including implementation of the mental and behavioral health provisions in the Older Americans Act Amendments of 2006, to provide grants to States for the delivery of mental health screening, and treatment services for older individuals and programs to increase public awareness and reduce the stigma associated with mental disorders in older individuals. APA also recommends that AoA designate an officer to administer mental health services for older Americans.

Caregivers.—Family caregivers play an essential role in providing long-term services and supports for the chronically ill and aging. For this reason APA supports the Lifespan Respite Care Program and urges Congress to appropriate \$50 million for this initiative in fiscal year 2012. In addition, the Secretary of HHS should ensure that State agencies and Aging and Disability Resource Centers (ADRCs) use the funds to serve all age groups, chronic conditions and disability categories equitably and without preference.

The agencies under this Subcommittee's jurisdiction provide critical support to APA's members, their home institutions, and their students and patients. The APA commends the Committee for accepting written testimony from public witnesses.

PREPARED STATEMENT OF THE AMERICAN PUBLIC HEALTH ASSOCIATION

The American Public Health Association (APHA) is the oldest and most diverse organization of public health professionals and advocates in the world dedicated to promoting and protecting the health of the public and our communities. We are pleased to submit our views on Federal funding for public health activities in fiscal year 2012.

Recommendations for Funding the Public Health Service

APHA's budget recommendations for the Public Health Service includes funding for the Centers for Disease Control and Prevention (CDC), the Health Resources and Services Administration (HRSA), the Substance Abuse and Mental Health Services Administration (SAMHSA), the Agency for Healthcare Research and Quality (AHRQ), and the National Institutes of Health (NIH). Together all of these agencies play a critical role in keeping Americans healthy.

CDC

APHA believes that Congress should support CDC as an agency—not just the individual programs that it funds. In the best judgment of the CDC Coalition—given the challenges and burdens of chronic disease, a potential influenza pandemic, terrorism, disaster preparedness, new and reemerging infectious diseases and our many unmet public health needs and missed prevention opportunities—we believe the agency will require funding of at least \$7.7 billion for CDC's "core programs" in fiscal year 2012. This request represents a 36 percent increase over fiscal year 2011 and a 31 percent increase over the President's fiscal year 2012 request. We are deeply disappointed with the more than \$740 million in cuts to CDC's budget authority included in the proposed fiscal year 2011 continuing resolution (CR). While CDC programs will receive significant new funding from the Prevention and Public Health Fund in fiscal year 2011, we are concerned that this funding would essentially supplant cuts made to CDC's budget authority. As you know the Prevention and Public Health Fund was intended to supplement and not supplant the base funding of our public health agencies and programs.

The President's fiscal year 2012 budget proposes to consolidate a number of chronic disease programs within CDC. APHA and other advocates are currently engaged in conversations with CDC and members of Congress to better understand what this consolidation will mean for the funding that is passed on to our State and local health agencies and the various programs our members have supported in the past. We look forward to working with Congress, the Administration and CDC to ensure that any effort to consolidate the programs leads to best health outcomes for the American people. We must ensure that CDC's National Center for Chronic Disease Prevention and Health Promotion has the resources it needs to assist our States and communities in their efforts to reduce the burden of chronic disease.

By translating research findings into effective intervention efforts, CDC has been a key source of funding for many of our State and local programs that aim to improve the health of communities. Perhaps more importantly, Federal funding through CDC provides the foundation for our State and local public health departments, supporting a trained workforce, laboratory capacity and public health education communications systems.

CDC also serves as the command center for our Nation's public health defense system against emerging and reemerging infectious diseases. With the potential onset of a worldwide influenza pandemic, in addition to the many other natural and man-made threats that exist in the modern world, the CDC has become the Nation's—and the world's—expert resource and response center, coordinating communications and action and serving as the laboratory reference center. States and communities rely on CDC for accurate information and direction in a crisis or outbreak. This has been demonstrated most recently by CDC's quick response and ongoing in-

vestigation into human infections with H1N1 flu (swine flu) in the United States and internationally.

CDC's National Center for Injury Prevention and Control works to prevent unintentional and violence-related injuries to minimize the consequences of injuries when they occur by researching the problem; identifying the risk and protective factors; developing and testing interventions; and ensuring widespread adoption of proven strategies. We urge you to ensure the agency has the resources it needs to address these leading causes of death and disability.

We must address the growing disparity in the health of racial and ethnic minorities. CDC is helping States address serious disparities in infant mortality, breast and cervical cancer, cardiovascular disease, diabetes, HIV/AIDS and immunizations. APHA is committed to ending health disparities and we encourage the Subcommittee to provide adequate funds for these efforts.

We also encourage the Subcommittee to provide adequate funding for CDC's National Center for Environmental Health. We ask that the Subcommittee to continue its recent efforts to expand and enhance CDC's capacity to help the Nation prepare for and adapt to the potential health effects of climate change by providing CDC with \$15 million for climate change and health activities. Expanded funding would allow CDC to provide technical assistance, training and tools to help State and local health officials and improve coordination and integration of climate change across CDC. We also urge the Committee to closely evaluate the significant cut made to CDC's Healthy Homes/Lead Poisoning Prevention and the National Asthma Control programs in the President's budget to ensure these programs have adequate funding to provide States and localities with the funding they need to protect public health.

HRSA

We request an overall funding level of \$7.65 billion for HRSA in fiscal year 2012. This recommendation represents a 22 percent increase over fiscal year 2011 and a 12 percent increase over the President's fiscal year 2012 request. We believe this level of funding is the minimum amount necessary for HRSA to continue to meet the healthcare needs of the American public. Over the past several years, HRSA has received mostly level funding, undermining the ability of its successful programs to grow. Additionally we are deeply disappointed with the more than \$1.2 billion in cuts made to the agency in the final fiscal year 2011 continuing resolution and the potential negative consequences for public health. Our fiscal year 2012 requested minimum level of funding will better allow the agency to carry out critical public health programs and services that reach millions of Americans, including training for public health and healthcare professionals, providing primary care services through community health centers, improving access to care for rural communities, supporting maternal and child healthcare programs, providing healthcare to people living with HIV/AIDS, and many more. However, much more is needed for the agency to achieve its ultimate mission of ensuring access to culturally competent, quality health services; eliminating health disparities; and rebuilding the public health and healthcare infrastructure.

HRSA operates programs in every State and thousands of communities across the country and is a national leader in providing health services for individuals and families. The agency serves as a health safety net for the medically underserved, including the 50 million Americans who were uninsured in 2009 and 50 million Americans who live in neighborhoods where primary healthcare services are scarce.

The \$7.65 billion fiscal year 2012 HRSA funding request is based upon recommendations provided by public health professionals to support HRSA programs including:

- Health Professions programs support the education and training of primary care physicians, nurses, dentists, optometrists, physician assistants, nurse practitioners, public health personnel, mental and behavioral health professionals, pharmacists, and other allied health providers; improve the distribution and diversity of health professionals in medically underserved communities; and ensure a sufficient and capable health workforce able to provide care for all Americans and respond to the growing demands of our aging and increasingly diverse population. In addition, the Patient Navigator Program helps individuals in underserved communities, who suffer disproportionately from chronic diseases, navigate the health system.
- Primary Care programs support more than 7,000 community health centers in every State and territory, improving access to preventive and primary care in geographically isolated and economically distressed communities. In addition, the health centers program targets populations with special needs, including migrant and seasonal farm workers, homeless individuals and families, and those living in public housing.

- Maternal and Child Health Flexible Maternal and Child Health Block Grants, Healthy Start and other programs provide services, including prenatal and post-natal care, newborn screening tests, immunizations, school-based health services, mental health services, and well-child care for more than 34 million uninsured and underserved women and children not covered by Medicaid or the Children's Health Insurance Program, including children with special needs.
- HIV/AIDS programs provide assistance to metropolitan and other areas most severely affected by the HIV/AIDS epidemic; support comprehensive care, drug assistance and support services for people living with HIV/AIDS; provide education and training for health professionals treating people with HIV/AIDS; and address the disproportionate impact of HIV/AIDS on women and minorities.
- Family Planning Title X programs provide reproductive healthcare and other preventive services for more than 5 million low-income women at over 4,500 clinics nationwide. These programs improve maternal and child health outcomes, prevent unintended pregnancies, and reduce the rate of abortions.
- Rural Health programs improve access to care for the 60 million Americans who live in rural areas. Rural Health Outreach and Network Development Grants, Rural Health Research Centers, Rural and Community Access to Emergency Devices Program, and other programs are designed to support community-based disease prevention and health promotion projects, help rural hospitals and clinics implement new technologies and strategies, and build health system capacity in rural and frontier areas.
- Special Programs include the Organ Procurement and Transplantation Network, the National Marrow Donor Program the C.W. Bill Young Cell Transplantation Program, and National Cord Blood Inventory. Strong funding would facilitate an increase in organ, marrow and cord blood transplantation.

Greater investment is necessary to sufficiently fund HRSA services and programs that continue to face increasing demands. We urge you to consider HRSA's role in building the foundation for health service delivery and ensuring that vulnerable populations receive quality health services, while continuing to strengthen our Nation's health safety net programs. By supporting, planning for and adapting to change within our healthcare system, we can build on the successes of the past and address new gaps that may emerge in the future.

AHRQ

We request a funding level of at least \$405 million for AHRQ for fiscal year 2012. This level of funding is needed for the agency to fully carry out its Congressional mandate to conduct, support, and disseminate research and translate research into knowledge and information that can be used to improve the health of all Americans. AHRQ focuses on improving healthcare quality, eliminating racial and ethnic disparities in health, reducing medical errors, and improving access and quality of care for children and persons with disabilities.

SAMHSA

APHA supports a funding level of \$3.671 billion for SAMHSA for fiscal year 2012. This funding level would provide support for substance abuse prevention and treatment programs, as well as continued efforts to address emerging substance abuse problems in adolescents, the nexus of substance abuse and mental health, and other serious threats to the mental health of Americans.

NIH

APHA supports a funding level of \$35 billion for the NIH for fiscal year 2012. The translation of fundamental research conducted at NIH provides some of the basis for community based public health programs that help to prevent and treat disease.

Conclusion

In closing, we emphasize that the public health system requires stronger financial investments at every stage. Successes in biomedical research must be translated into tangible prevention opportunities, screening programs, lifestyle and behavior changes, and other interventions that are effective and available for everyone. Without a robust and sustained investment in our Nation's public health agencies, we will fail to meet the mounting health challenges facing our Nation.

PREPARED STATEMENT OF THE AMERICAN PUBLIC POWER ASSOCIATION

The American Public Power Association (APPA) appreciates the opportunity to submit this statement supporting funding for the Low-Income Home Energy Production Assistance Program (LIHEAP) for fiscal year 2012.

APPA has consistently supported an increase in the authorization level for LIHEAP. The Administration's fiscal year 2012 budget requests \$2.57 billion for LIHEAP. APPA supports extending the current level of \$5.1 billion for the program.

APPA is the national service organization representing the interests of over 2,000 municipal and other State and locally owned utilities throughout the United States (all but Hawaii). Collectively, public power utilities deliver electricity to 1 of every 7 electricity consumers (approximately 46 million people), serving some of the Nation's largest cities. However, the vast majority of APPA's members serve communities with populations of 10,000 people or less.

APPA is proud of the commitment that its members have made to their low-income customers. Many public power systems have low-income energy assistance programs based on community resources and needs. Our members realize the importance of having in place a well-designed low-income customer assistance program combined with energy efficiency and weatherization programs in order to help consumers minimize their energy bills and lower their requirements for assistance. While highly successful, these local initiatives must be coupled with a strong LIHEAP program to meet the growing needs of low-income customers. In the last several years, volatile home-heating oil and natural gas prices, severe winters, high utility bills as a result of dysfunctional wholesale electricity markets and the effects of the economic downturn have all contributed to an increased reliance on LIHEAP funds. Even at \$5.1 billion, LIHEAP cannot provide assistance to all who qualify for the program. Cutting this program by \$2.5 billion would have very serious consequences for those who rely on the program.

Also when considering LIHEAP appropriations this year, we encourage the subcommittee to provide advanced funding for the program so that shortfalls do not occur in the winter months during the transition from one fiscal year to another. LIHEAP is one of the outstanding examples of a State-operated program with minimal requirements imposed by the Federal Government. Advanced funding for LIHEAP is critical to enabling States to optimally administer the program.

Thank you again for this opportunity to relay our support for increased LIHEAP funding for fiscal year 2012.

PREPARED STATEMENT OF THE AMERICAN SOCIETY FOR MICROBIOLOGY

The American Society for Microbiology (ASM) is pleased to submit the following testimony on the fiscal year 2012 appropriation for the Centers for Disease Control and Prevention (CDC). The ASM is the largest single life science organization in the world with over 38,000 members. The ASM mission is to enhance the science of microbiology, to gain a better understanding of life processes and to promote the application of this knowledge for improved health and environmental well being.

The ASM supports the proposed fiscal year 2012 budget of \$11.3 billion for the CDC, a 3.4 percent increase over the fiscal year 2010 funding level. The budget recognizes the importance of maintaining a strong infrastructure to address infectious disease prevention and control. The CDC's role, in partnership with State and local health departments and international partners, is to monitor for known and emerging infectious disease threats through surveillance and laboratory diagnosis, and to develop control and prevention strategies for these diseases. Examples include vaccine preventable diseases, foodborne diseases, pandemic influenza, vectorborne and zoonotic diseases, healthcare acquired infections (HAIs) and antimicrobial resistance. The proposed fiscal year 2012 budget addresses these threats and provides targeted resources for them.

The fiscal year 2012 proposed budget includes an increase in funding for HIV/AIDS, sexually transmitted diseases (STD), tuberculosis (TB), and hepatitis, and gives the States added flexibility to shift funding among these programs based on local priorities. The ASM supports this approach. The ASM also supports the \$68 million increase in funding for emerging and zoonotic diseases, including \$40 million in funding from the Prevention and Public Health Fund to enhance epidemiology and laboratory capacity in State health departments.

However, caution must be taken regarding any reductions in effort for "low impact, disease specific programs" as proposed in the fiscal year 2012 budget. Experience indicates that an emerging public health threat can occur with almost any pathogen, and capacity must be sustained with this possibility in mind. Examples of such complacency include the reemergence of drug resistant tuberculosis in the 1990s and West Nile virus in 1999. The proposed elimination of prion activities at CDC could have such an impact, as these diseases are related to human variant Creutzfeldt Jakob Disease (vCJD) and to chronic wasting disease, which is an emerging animal health problem in several areas of the United States.

The ASM supports investments to address healthcare associated infections. CDC provided resources through the American Recovery and Reinvestment Act (ARRA) to develop programs for surveillance and prevention of HAIs, which have resulted in substantial HAI reductions in these infections with significant cost savings to the healthcare system. These investments must be sustained after ARRA funding ends, and the proposed \$47 million for HAIs would accomplish this goal.

The ASM supports the \$8.7 million increase in funding for food safety. The CDC recently released new estimates of foodborne diseases, concluding that 1 in 6 people in the United States get sick each year (about 48 million people). The delayed recognition of the widespread outbreaks of salmonellosis associated with eggs during 2010 demonstrates the need to sustain and enhance vigilance for foodborne outbreaks. In that outbreak, over 1,900 confirmed illnesses were reported (likely a small percentage of actual cases) and 500 million eggs were recalled. CDC's surveillance systems will also play a pivotal role in assessing the success of programs developed as a result of the recently passed Food Safety Modernization Act.

The ASM is concerned about the following proposed reductions in the fiscal year 2012 CDC budget:

- There is a substantial decline in preparedness funding, including a \$72 million cut in funds for State and local preparedness grants. Such declines will have a significant impact on the ability of frontline public health workers to be able to respond to all hazard emergencies at a time of restrained budgets at the State and local level. The ASM recommends such grants be maintained at fiscal year 2010 funding levels.
- The proposed elimination of funding for the CDC genomics program should be restored. Public health genomics is an area of growing importance, including the ability to identify risk factors for enhanced susceptibility or resistance to infectious diseases. Such genetic factors have important implications for disease prevention and treatment, and must be tied to epidemiologic investigations and disease surveillance efforts.
- The ASM does not endorse the elimination of targeted funding for CDC's antimicrobial resistance (AR) activities and the transfer of these funds into the overall budget for emerging infections. While ASM appreciates the need for funding flexibility, antimicrobial resistance is a substantial public health problem that leads to significant morbidity and death and markedly increases healthcare costs. To address this threat, sustained dedicated funding is necessary.

CDC Infectious Disease Programs Protect Public Health

Infectious diseases cause about one-fourth of all deaths globally, more than 11 million people, over half of them children. In the United States, influenza and pneumonia account for more than 56,000 deaths each year. Of the 1.1 million people living in the United States living with HIV/AIDS, about 21 percent do not know that they are HIV positive; there are more than 56,000 new HIV infections annually. Last year, the CDC responded to multiple disease outbreaks and incidents that included surveillance of cholera in post earthquake Haiti and activation of CDC's Emergency Operations Center as part of the Federal response to the gulf oil spill.

In the United States, the economic and societal costs of infectious diseases are significant, exacerbated by previously unknown microbial pathogens, rising drug resistance among pathogens and increasing travel and commerce between geographic areas. The CDC Office of Infectious Diseases leads United States efforts to stop or minimize the onslaught of infectious diseases, with highly qualified personnel at three national centers that specialize in (1) Emerging and Zoonotic Infectious Diseases; (2) HIV/AIDS, Viral Hepatitis, STD, and TB Prevention; or (3) Immunization and Respiratory Diseases.

The ASM endorses the proposed fiscal year 2012 budget for key programs at CDC, including the following:

Emerging Infectious Diseases/Antimicrobial Resistance.—CDC is a world leader in detecting and preventing emerging and reemerging infectious diseases, a role which depends on strong science capabilities and readiness to confront the unexpected. CDC's infrastructure and partnerships have dealt quickly with the more than three dozen new human pathogens of medical significance identified in the past 30 years. Recent CDC advances include developing one of the first candidate vaccines against all four species of dengue virus, now in human trials, and a plan to screen U.S. blood donations for West Nile virus. fiscal year 2012 funding will support planned EID activities like the development and deployment of improved diagnostic tests for plague, dengue and chikungunya. About 75 percent of recently emerging human infectious diseases originated in animals, making zoonotic diseases another high priority at CDC, along with vectorborne diseases spread by mosquitoes, ticks, fleas and

other vectors. Two reports last year illustrate the critical nature of CDC's EID activities: In Florida, an estimated 5 percent of Key West's population showed recent exposure to the dengue fever virus; and the new antimicrobial resistance gene called New Delhi metallo β lactamase (NDM-1), first detected in 2008, is spreading to additional countries.

Increased fiscal year 2012 funding will support CDC efforts against the alarming (and rising) number of pathogens now resistant to antimicrobial drugs. As part of the U.S. Interagency Task Force on Antimicrobial Resistance, CDC distributes both intramural and extramural AR funding for surveillance, prevention, and research activities. Agency surveillance networks routinely collect data on cases of resistant pathogens. CDC provides epidemiology and laboratory support for outbreaks of AR organisms, and distributes educational materials to promote appropriate use of antimicrobials. Investments in AR programs are cost effective; one study estimated that the additional medical cost per U.S. patient infected with an AR pathogen ranges from about \$19,000 to nearly \$30,000. Another estimate concluded that preventing a single case of multidrug resistant (MDR) tuberculosis can save up to \$700,000. In fiscal year 2010, CDC diagnosed and treated about 1,000 cases of tuberculosis (including 40 MDR) among overseas immigrant applicants and U.S. bound refugees, saving States an estimated \$45 million.

HIV/AIDS.—Scientific advances announced last year have added new tools to CDC's numerous HIV prevention activities; using a vaginal microbicide or daily doses of an oral antiretroviral drug (PrEP) both lowered risk of infection in clinical trials. In July 2010, the Administration released its National HIV/AIDS Strategy for the United States (NHAS). Proposed fiscal year 2012 budget increases would invest substantially in the NHAS 5 year goals to reduce new infections: (1) lower the annual number of new infections by 25 percent, from 56,300 to 42,225; (2) reduce the HIV transmission rate by 30 percent, from 5 persons infected per 100 people with HIV to 3.5 persons infected; and (3) increase from 79 to 90 the percentage of people living with HIV who know their serostatus.

Viral Hepatitis.—Proposed fiscal year 2012 increases for viral hepatitis prevention would boost CDC surveillance in 10 high burden State and local health departments. Prevention of viral hepatitis has been successful in recent years, in large part due to vaccines against hepatitis A and B viruses. HAV incidence has decreased approximately 92 percent nationwide since 1995; rates of HBV have been reduced far below the original Healthy People 2010 goal of 4.5 cases per 100,000. In the first half of fiscal year 2010, CDC funded health departments administered over 130,000 doses of HBV vaccine to at risk adults and ensured that 87 percent of infants born to HBsAg+ women were vaccinated. Incidence of hepatitis C infections has dropped from more than 45,000 cases annually to an estimated 20,000, primarily as a result of screening the U.S. blood supply and falling case numbers among intravenous drug users. However, 2.7–3.9 million Americans have HCV, most unaware of their infection. The fiscal year 2012 budget would address last year's Institute of Medicine report, which concluded that public health programs have insufficient hepatitis related resources and that efforts to prevent and control viral hepatitis are not adequate.

Sexually Transmitted Diseases.—Fiscal year 2012 increases would strengthen CDC's STD infrastructure, which supports 65 State and local prevention programs, and sustain the CDC's surveillance of drug resistant STD pathogens like that causing gonorrhea. Reducing STD infections is highly cost effective; for example, CDC estimates that reductions in gonorrhea and syphilis from 1990 to 2003 saved the U.S. economy \$5 billion. Cost savings with chlamydia screening in sexually active young women are an estimated \$2,500–\$37,000 per year. Aggressive public health efforts to prevent STDs have had positive results; for instance, from 1999 to 2009, rates of primary and secondary syphilis among females declined by 30 percent, while congenital syphilis dropped 32 percent. Yet, in general, STDs in the United States persist at unacceptable levels: CDC estimates that there are approximately 19 million new STD infections each year, which cost the U.S. healthcare system \$16.4 billion annually (2009 figures).

CDC Campaigns Prevent Disease in the United States, Worldwide

Healthcare Associated Infections.—In the United States, 1 in 20 hospital patients get an infection during medical treatment. Of the nearly 2 million infections acquired in some type of healthcare setting annually, almost 100,000 are fatal. A 2009 CDC report estimates that each year U.S. hospitals spend between \$28 billion and \$35.7 billion to treat often preventable HAIs. Depending on the effectiveness of infection control interventions used, the CDC expects that prevention measures could save from \$5.7 billion–\$31.5 billion of these costs. To illustrate, intensive care units have reduced bloodstream infections in patients with central lines by 58 percent

since 2001, using CDC recommended infection control procedures and saving up to 27,000 lives and \$1.8 billion. The proposed fiscal year 2012 budget would significantly increase support for the CDC's HAI activities and its National Health Care Safety Network (NHSN) that had provided monitoring capacity to more than 3,900 health facilities by the end of 2010. With the increased funding, routine NHSN participation will expand from 2,500 to 6,500 healthcare settings (5,500 hospitals; the rest include hemodialysis and long-term care facilities). In March this year, the CDC awarded \$10 million for HAI research at five academic medical centers, as part of its Prevention Epicenter program.

Immunization.—The Administration's fiscal year 2012 CDC budget invests substantial resources into vaccine preventable diseases, continuing national immunization campaigns against diseases like seasonal and pandemic influenza. The number of lives saved and medical costs reduced can be considerable. According to the CDC, "for every birth cohort who receives seven [routine childhood] vaccines . . . society saves \$9.9 billion in direct medical costs; over 33,500 lives are saved; and 14 million cases of disease are prevented." Other examples of returns on CDC investment include vaccination against *Haemophilus influenzae* type b (Hib), responsible for a 99 percent decline in this leading cause of bacterial meningitis in children under age 5, for an estimated medical cost savings of \$950 million per year plus another \$1.14 billion of retained earnings by unpaid caregivers. In the past year, CDC reported that 3 years of rotavirus vaccinations had reduced severe rotavirus disease by 85 percent, and helped develop the guidelines for deploying the new pneumococcal vaccine expected to greatly reduce pneumonia and ear infections among children. In December, CDC launched its Vaccine Tracking System to follow vaccine orders from manufacturer to distributor to health providers.

Global Health.—Lower respiratory tract infections, diarrheal diseases, HIV/AIDS, TB and malaria together account for nearly one-fifth of deaths globally. CDC is a lead partner in the Administration's Global Health Initiative, underscoring the importance of infectious diseases no matter where outbreaks occur. The fiscal year 2012 budget includes increase of funds for global polio eradication, an international campaign begun in 1988 that is nearing victory with only four countries still harboring endemic disease. Last year, there were about 900 cases reported, declining from more than 350,000 in 1988. fiscal year 2012 funds will purchase 254 million doses of oral polio vaccine for use in mass immunization campaigns in Southeast Asia, Africa and Europe, to achieve CDC's target of zero polio endemic countries by the end of 2012. Funding will support the CDC vaccination campaign toward a 90 percent reduction in global measles related mortality; by 2008, CDC and its partners had helped reduce measles deaths by 78 percent, from an estimated 733,000 in 2000 to about 164,000.

Quarantine and migration related activities also are part of the agency's multi level strategies in global health; CDC operates 20 U.S. quarantine stations and responds to outbreaks in refugee camps overseas. Travel and trade allow pathogens to move quickly. The 2009 "swine flu" spread to 30 countries within 6 weeks. About 1.8 million airline passengers cross international borders daily, and about half of international travelers worldwide have some kind of health problem while traveling. An estimated 50,000–70,000 refugees and 1.2 million immigrants resettle in the United States each year, while more than 2 million people travel to or through this country by air, sea, or land daily.

PREPARED STATEMENT OF THE AMERICAN SOCIETY FOR MICROBIOLOGY

The American Society for Microbiology (ASM) wishes to submit the following written testimony on the fiscal year 2012 appropriation for the National Institutes of Health (NIH). The ASM is the largest single life science organization with over 38,000 members. Its mission is to enhance the science of microbiology, to gain a better understanding of life processes and to promote the application of this knowledge for improved health and environmental well being.

The ASM urges Congress to support strong Federal funding for biomedical research and to provide \$35 billion in funding for the NIH in fiscal year 2012. Continued investments in science and public health programs are critical to the Nation's health, economic growth, national security and global leadership. Acquiring knowledge at the frontiers of science is the basis for new technologies, medical discoveries, new industries and high value jobs. Investments in biomedical research lead to more effective treatments, preventions and cures for chronic and infectious diseases, improving the quality of life for people everywhere. Reducing funding for research project grants will slow medical progress on a myriad of diseases, adversely affecting human life. Attracting and retaining scientists and maintaining the vitality of

the research enterprise will become more difficult if the Nation does not remain committed to sustained and predictable funding for research and training. We, therefore, urge Congress to make increased appropriations for biomedical research a national priority as the Federal budget is considered for the coming fiscal year.

NATIONAL INSTITUTES OF HEALTH: A CRUCIAL INVESTMENT FOR THE FUTURE

The NIH is a primary contributor to growing the Nation's economy and ensuring U.S. leadership in science. The NIH expends 97 percent of its annual budget on R&D activities through its 27 centers and institutes. NIH funding helps foster innovation among more than 300,000 research personnel at over 3,000 universities and research institutions, with about 6,000 scientists working in NIH's own laboratories.

Life saving successes in biomedical research depend on NIH support: for example, the development last year of a new 2 hour diagnostic test for tuberculosis and drug resistant TB bacteria; a potential drug against malaria parasites, evidence that an anti-HIV treatment could also prevent infection, research suggesting a role for intestinal bacteria in obesity, and the 2010 Nobel Prize winning methods to synthesize compounds that have already proven effective against HIV and herpes virus. NIH funded research improves the health of our communities, represents investment in local and national economic growth and advances U.S. science and medicine.

Investing in Scientific Innovation, Advancing Medical Knowledge

NIH funded research has repeatedly reshaped medicine and continues to enhance public health. NIH routinely identifies new research initiatives and pursues transformative research. NIH recently delineated five priority areas with particular promise for safeguarding our future, including:

- High throughput technologies.*—DNA sequencing, nanotechnology and other computer supported technologies can generate massive data sets that enable comprehensive approaches to disease, like the NIH microbiome project to understand how interactions with the microbes that live on and in the human body influence health and disease.
- Translational medicine.*—NIH programs will increasingly focus on translating basic scientific discoveries into new clinical diagnostics and treatments (bench to bedside).
- Informing healthcare reform.*—With U.S. expenditures on healthcare approaching 20 percent of our gross domestic product, NIH research areas like personalized medicine and pharmacogenomics seek cost effective solutions through disease treatment and prevention tailored to individual patients.
- Global health.*—In addition to NIH's ongoing efforts against AIDS, tuberculosis and malaria, more resources will go toward combating neglected tropical diseases that devastate low income countries.
- Reinvigorating the biomedical research community.*—NIH is reevaluating the Nation's future scientific workforce needs in terms of its own training programs, as well as optimizing NIH's extramural research investments to more effectively discover innovative medical solutions.

THE IMPORTANCE OF INVESTIGATOR INITIATED RESEARCH

The majority of NIH funds are distributed across the country to extramural researchers through grants, contracts and fellowships. Investigator initiated, competitively awarded Research Project Grants (RPGs) are the single most effective mechanism for ensuring research innovation. Early in the decade, an average of 1 out of 3 grant applications were funded. In recent years, the success rate has fallen to roughly 1 in 5, with only a 15 percent success rate estimated for fiscal year 2011, despite an abundance of research opportunities.

Scientific advances require investigator inspiration and persistence often over years of research. For example, a large share of the research awarded the 2010 Nobel Prize in Chemistry occurred in a laboratory supported since 1979 by the National Institute of General Medical Sciences (NIGMS). Success developing the DNA based TB rapid diagnostic test announced last year followed more than 8 years of National Institute of Allergy and Infectious Diseases (NIAID) support. NIH funding also enables transformative research that has a higher degree of risk for failure, but potential for huge scientific rewards, like recipients of the relatively new EUREKA program (Exceptional, Unconventional Research Enabling Knowledge Acceleration) managed by NIGMS. Among this year's new NIGMS grants are projects designed to decipher the genetic code in yeast and to use bacterial components to induce patient specific stem cells that facilitate gene therapy.

At NIH, long range strategies for research success include workforce development and mentoring young researchers. NIAID, for example, met its own target of sup-

porting “new investigators” in fiscal year 2009 by funding about 20 percent of those who applied for R01 grants as first time principal investigator. NIGMS, which distributes 70 percent of its budget to research project grants, contributes an additional 10 percent to underwrite institutional training grants and fellowships that specifically fulfill its mission to train the next generation of medical scientists. In addition, NIGMS funds approximately 50 percent of Ph.D. research training positions at NIH, including the Medical Scientist Training (M.D.-Ph.D.) program. Additional NIH grant programs focus on K–12 education in science, technology, engineering and mathematics (STEM), to foster a future technical workforce.

The NIH regularly identifies research intended to ultimately produce public health benefits. In fiscal year 2009, NIAID released 33 new funding opportunity announcements that are already producing results in selected areas, including innovative approaches to vaccine development against HIV, malaria and hepatitis C, and clinical trials specifically designed to counter the threat of antimicrobial resistance among pathogens. Research concepts reviewed periodically by NIAID advisory councils may anticipate potential research initiatives for upcoming funding cycles. For example, concepts approved in September 2010 included research to prevent the spread of drug resistant pathogens; support for Functional Genomics Research Centers that will generate massive genetic data sets readily available to the broad scientific community; improved diagnostics for Lyme disease; and a “pluripotent approach” for sexual and reproductive health that might combine contraceptive methods with microbicides, vaccine or other disease preventives.

NIH Research to Address Threats of Infectious Diseases and Antimicrobial Resistance

Infectious diseases cause approximately 26 percent of all deaths worldwide, more than 11 million people annually. Each year infectious diseases kill approximately 6.5 million children, most in developing countries. These preventable diseases also greatly impact public health systems in the United States. For example, influenza and pneumonia account for more than 56,000 deaths annually, while each year there are more than a million new cases of sexually transmitted diseases. Despite ground breaking triumphs against infectious diseases over decades of research, both predictable and unexpected infectious agents continue to challenge medical science. In recent years of flat funding, NIAID has had to respond to additional public health threats like bioterrorism and unforeseen infectious diseases, by steadily expanding its research portfolio and its capabilities to recognize and quickly counter newly emerging and reemerging diseases in the United States and elsewhere. The scope and significance of NIAID sponsored research cannot be overstated.

The emergence of drug resistant microbial pathogens seriously complicates efforts to stop or minimize infectious diseases. The magnitude of the problem elevates the public health significance of antimicrobial resistance. Examples of clinically important microbes that are rapidly developing resistance to available drugs include bacteria that cause pneumonia, ear infections and meningitis, skin, bone, lung and bloodstream infections, urinary tract infections, foodborne infections and infections in healthcare settings. In recent years there have been dramatic examples like chloroquine resistant malaria, methicillin resistant *Staphylococcus aureus* (MRSA) infection and multidrug resistant and extensively drug resistant tuberculosis. Ten percent of all hospitalized patients in this country have or develop resistant infections, adding \$55 billion in annual healthcare costs. The public health burden of MRSA is enormous with over 90,000 MRSA infections per year in the United States. As a result, more NIH funding must be allotted to relevant research. In 2010 NIAID announced four new contracts for large scale clinical trials (making a total of eight trials) focused on treatment alternatives for diseases for which antibiotics are prescribed most often (e.g., middle ear infections). Also in 2010, NIAID reported a newly identified MRSA toxin, the only MRSA toxin currently known to destroy specific human immune cells and a possible target of future drugs.

HIV/AIDS.—Since 1981, when the U.S. epidemic began, HIV/AIDS has killed more than 565,000 people in the United States. Each year there are about 2 million AIDS related deaths worldwide and an additional 2.7 million become newly infected, including about 56,000 new infections annually in the United States. An estimated 33 million are living with HIV/AIDS, over 1 million of those in this country. In large part due to NIH support, medical science now offers rising hope amidst these grim statistics, as those with HIV/AIDS live longer and better. In 2010, NIAID funded researchers reported several studies that have been called landmarks in the fight against this difficult disease:

- Preexposure prophylaxis (PrEP) with a daily dose of an approved anti-HIV drug reduces the risk of infection among men who have sex with men; studies of other at risk populations continue.

- After nearly 15 years of research, scientists discovered the first vaginal microbicide gel that gives women some protection against HIV infection.
- Various research groups have discovered at least eight antibodies that can stop HIV from infecting human cells in the laboratory, which could help scientists design effective vaccines.
- A study in Cambodia demonstrated that people coinfecting with HIV and tuberculosis can benefit from starting antiretroviral therapy earlier than originally believed (antiretroviral treatment can worsen the symptoms of coinfections, so timing is critical).

Emerging Infectious Diseases.—Since 2003, NIAID has had principal responsibility for NIH's research and development of medical countermeasures against radiological, nuclear, chemical and biological terrorist threats. NIAID's programs on biodefense and emerging/reemerging infectious diseases are inevitably intertwined. Researchers study hemorrhagic fevers caused by Ebola and other viruses, West Nile virus, prion diseases, influenza viruses, anthrax, and dozens of other infectious diseases, seeking vaccines, therapeutics, and diagnostics to prevent or curb disease outbreaks. Last year, for instance, NIAID scientists announced a new, quick method called real time quaking induced conversion assay (RT QuIC) to detect prions, which cause fatal brain diseases like mad cow disease in cattle, Creutzfeldt Jakob disease in humans, and scrapie in sheep. Other researchers discovered a new form of murine prion disease that resembles a form of human Alzheimer's disease.

Last August, after more than a decade of work by NIAID scientists, a dengue vaccine began human clinical testing; the virus infects about 50 million to 100 million people annually. NIAID also awarded new contracts to private industry to develop delivery systems for new vaccines against anthrax and dengue fever; clinical trials of the three vaccines should begin within 3 years. Two other experimental vaccines showed promise against Marburg virus (cause of hemorrhagic fever with a fatality rate up to 80 percent) and Ebola virus (up to 90 percent fatality).

National Security and Research.—Beginning in the late 1990s and especially following 2001, funding for research in the Department of Defense related to global diseases that impact U.S. military on foreign soil as well as protection against biothreats on U.S. soil decreased. This research is now primarily entrusted to NIAID and other NIH institutes, FDA and CDC. Research related to defense is interdependent on advances in other areas of research, especially those related to emerging infections. Reports issued recently by the Institute of Medicine and the National Biodefense Science Board emphasize the need to properly fund these agencies for medical countermeasure development.

Genomics.—NIAID and NIGMS sponsor genomic research for improving human health. At NIGMS, investigators are using human genetic information to explain and identify individuals' reactions to certain drugs—research called pharmacogenetics, which is focused on the NIH goal of cost effective “predictive, personalized, and preemptive medicine.” NIAID supported genomic research programs include genome sequencing centers and bioinformatics resource centers. By the end of 2010, the Institute's two Structural Genomics Centers for Infectious Diseases had determined 500 3-D protein structures from microorganisms on the NIAID Category A–C priority lists or otherwise considered major human pathogens.

Global Health.—Infectious diseases travel easily across international borders, and the economic stability of nations can be shaken by high rates of morbidity and mortality from such diseases. Fiscal year 2009 marked the 30th anniversary of the Institute's International Collaborations in Infectious Disease Research (ICIDR) program. That year NIAID supported 643 international projects in 97 countries, with 72 percent of the funds invested in HIV/AIDS research. In mid 2010, NIAID announced funding to establish 10 new malaria research centers around the world. NIAID supported researchers recently developed a chemical that may prove to be a new malaria drug; it has more than a decade since the last new class of antimalarials became available against a disease that kills nearly 1 million people every year. Preliminary data suggest that the new compound might be effective as a single dose, rather than the current standard treatment of multiple doses over several days. Also last year, other NIAID grantees described a previously unknown metabolic pathway used by malaria parasites to survive inside human blood cells.

CONCLUSION

For over a century, NIH funded discoveries have saved lives, stimulated private industry and fostered the next generation of scientists and physicians. More than 130 Nobel Prize winners have received support from NIH, but more importantly, the health of millions worldwide has been improved through NIH programs. NIH investments have also yielded remarkable financial rewards, from basic research that

helped launch the biotech industry to the recent development of a highly effective meningitis vaccine that each year saves an estimated \$950 million in medical costs and another \$1.14 billion in patient/caregiver earnings. The ASM strongly recommends that Congress support innovation in the medical sciences and increase funding for the National Institutes of Health in fiscal year 2012.

PREPARED STATEMENT OF THE AMERICAN SOCIETY FOR NUTRITION

The American Society for Nutrition (ASN) appreciates the opportunity to submit testimony regarding fiscal year 2012 appropriations for the National Institutes of Health (NIH) and the National Center for Health Statistics (NCHS). ASN is the professional scientific society dedicated to bringing together the world's top researchers, clinical nutritionists and industry to advance our knowledge and application of nutrition to promote human and animal health. Our focus ranges from the most critical details of nutrition research to broad societal applications. ASN respectfully requests \$35 billion for NIH, and we urge you to adopt the President's request of \$162 million for NCHS in fiscal year 2012.

Basic and applied research on nutrition, nutrient composition, the relationship between nutrition and chronic disease, and nutrition monitoring are critical to the health of all Americans and the U.S. economy. Awareness of the growing epidemic of obesity and the contribution of chronic illness to burgeoning healthcare costs has highlighted the need for improved information on dietary components, dietary intake, strategies for dietary change and nutritional therapies. The health costs of obesity alone are estimated at \$147 billion each year. This enormous health and economic burden is largely preventable, along with the many other chronic diseases that plague the United States. It is for this reason that we urge you to consider these recommended funding levels for two agencies under the Department of Health and Human Services that have profound effects on nutrition research, nutrition monitoring, and the health of all Americans—the National Institutes of Health and the National Center for Health Statistics.

National Institutes of Health

The National Institutes of Health (NIH) is responsible for conducting and supporting 90 percent (approximately \$1 billion) of federally funded basic and clinical nutrition research. Nutrition research, which makes up about 4 percent of the NIH budget, is truly a trans-NIH endeavor, being conducted and funded across multiple Institutes and Centers. In order to fulfill the full potential of biomedical research, including nutrition research, ASN recommends an fiscal year 2012 funding level of \$35 billion for the agency, a modest increase over the current funding level of \$34 billion (including supplemental appropriations). This increase is necessary to maintain both the existing and future scientific infrastructure. Although the discovery process produces tremendous value, it often takes a lengthy and unpredictable path. Economic stagnation is disruptive to training, careers, long range projects and ultimately to progress. NIH needs sustainable and predictable budget growth to achieve the full promise of medical research to improve the health and longevity of all Americans and continue our Nation's dominance in this area.

NIH and its grantees have played a major role in the growth of knowledge that has led to an unprecedented number of scientific breakthroughs that have transformed our understanding of human health, helping Americans to live longer, healthier and more productive lives. Many of these discoveries are nutrition-related and have impacted the way clinicians prevent and treat heart disease, cancer, diabetes and other chronic diseases. By 2030 the number of Americans age 65 and older is expected to grow to 72 million, and the incidence of chronic disease will also grow. Sustained support for nutrition research is required if we are to successfully confront the healthcare challenges associated with an older population.

CDC National Center for Health Statistics

The National Center for Health Statistics (NCHS), housed within the Centers for Disease Control and Prevention (CDC), is the Nation's principal health statistics agency. The NCHS provides critical data on all aspects of our healthcare system, and it is responsible for monitoring the Nation's health and nutrition status through surveys such as the National Health and Nutrition Examination Survey (NHANES). Nutrition and health data are essential for tracking the nutrition, health and well being of the American public, especially for observing nutritional and health trends in our Nation's children. Through learning both what Americans eat and how their diets directly affect their health, the NCHS is able to monitor the prevalence of obesity and other chronic diseases in the United States and track the performance of preventive interventions, as well as assess consumption of "nutrients of concern"

such as Vitamin D and calcium. Data such as these are critical to guide policy development in the area of health and nutrition.

To continue support for the agency and its important mission, ASN recommends a fiscal year 2012 funding level of \$162 million for the agency. Flat and decreased funding levels threaten the collection of this important information, most notably vital statistics and the NHANES. Moreover, nearly 30 percent of the funding for NHANES comes from other Federal agencies such as the NIH and the USDA Agricultural Research Service. When these agencies face flat budgets or worse, budget cuts, they withdraw much-needed support for NHANES, placing this valuable resource in peril. Sustained funding for NCHS can help to ensure uninterrupted collection of vital health and nutrition statistics.

Thank you for your support of the National Institutes of Health (NIH) and the National Center for Health Statistics (NCHS), and thank you for the opportunity to submit testimony regarding fiscal year 2012 appropriations. Please contact Sarah Ohlhorst, MS, RD, Director of Government Relations, if ASN may provide further assistance. She can be reached at address: 9650 Rockville Pike, Bethesda MD 20814; telephone number: 301.634.7281 or email address: sohlhorst@nutrition.org.

PREPARED STATEMENT OF THE AMERICAN SOCIETY FOR PHARMACOLOGY &
EXPERIMENTAL THERAPEUTICS

The American Society for Pharmacology and Experimental Therapeutics (ASPET) is pleased to submit written testimony in support of the National Institutes of Health (NIH) fiscal year 2012 budget. ASPET is a 5,100 member scientific society whose members conduct basic and clinical pharmacological research within the academic, industrial and government sectors. Our members discover and develop new medicines and therapeutic agents that fight existing and emerging diseases, as well as increase our knowledge regarding how therapeutics affects humans.

For fiscal year 2012, ASPET supports a \$35 billion budget for the NIH. Research funded by the NIH improves public health, helps stimulate our economy and improves global competitiveness. Sustained growth for the NIH should be an urgent national priority. Flat funding or cuts to the NIH budget will delay cures, eliminate jobs, and jeopardize American leadership and innovation in biomedical research.

A \$35 billion budget for the NIH in fiscal year 2012 will help restore some of the lost opportunities and purchasing power since 2003, when Congress finished a bipartisan effort of doubling the NIH budget. Currently, the NIH cannot begin to fund all the high quality research that needs to be done. At the moment only one-in-five research projects can be supported. The situation has now reached a critical point:

- Over the past 6 years, the number of research project grants funded by NIH has declined almost every year.
- NIH funds 2,000 fewer grants in total than in fiscal year 2004.
- NIH made 1,000 fewer competing (new and renewed) awards in 2010 than it did in 2003.
- Success rates for new applications have fallen for three straight years.

If flat funding continues, or if additional cuts are made to the NIH budget for fiscal year 2012, important research that improves the quality of life, offers life-saving new therapeutics, and ultimately reduces healthcare costs will be delayed or stopped. International competitors will continue to gain on this highly innovative U.S. enterprise, and we will lose a generation of young scientists who see no prospects for careers in biomedical research. Flat or reduced funding for NIH will mean that the agency would have to dramatically reduce new awards and many research projects in progress would not receive sufficient funding to complete the work, thus representing a waste of valuable research resources.

An fiscal year 2012 NIH budget of \$35 billion would help to restore momentum to NIH funding. Scientific discovery takes time. As recent experience has shown from the post-doubling experience and more recent stimulus funding in 2009 and 2010, “boom and bust” cycles of rapid funding followed by significant periods of stagnation or retraction in the NIH budget diminish scientific progress. A \$35 billion fiscal year 2012 NIH budget will help the agency manage its research portfolio effectively without too much disruption of existing grants to researchers throughout the country. The NIH, and the entire scientific enterprise, cannot rationally manage boom or bust funding cycles. Only through steady, sustainable and predictable funding increases can NIH continue to fund the highest quality biomedical research to help improve the health of all Americans and continue to make significant economic impact in many communities across the country. An fiscal year 2012 NIH budget of \$35 billion will help the NIH move to more fully exploit promising areas of biomedical research and translate the resulting findings into improved healthcare.

Investing in NIH Improves Human Health

Diminished funding for NIH will mean a loss of scientific opportunities to discover new therapeutic targets and will create disincentives to young scientists to commit to careers in biomedical science. A \$35 billion fiscal year 2012 NIH budget would provide the various institutes that make up the NIH with an opportunity to fund more high quality and innovative research in many disease areas. Earlier and significant investments in NIH research have been instrumental in improving human health:

- Parkinson's disease is estimated to afflict over 1 million Americans at an annual cost of \$26 billion. The discovery of Levodopa was a breakthrough in treating the disease and allows patients to lead relatively normal, productive lives. It is estimated that treatments slowing the progress of disease by 10 percent could save the United States \$327 million a year. Current treatments slow progression of disease, but more research is needed to identify the causes of the disease and develop better therapies.
- More than 38 million Americans are blind or visually impaired, and that number will grow with an aging population. Eye disease and vision loss cost the United States \$68 billion annually. NIH funded research has developed new treatments that delay or prevent diabetic retinopathy, saving \$1.6 billion a year. Discovery of gene variations in age related macular degeneration could result in new screening tests and preventive therapies.
- Almost 5 million Americans suffer from Alzheimer's disease at annual costs of more than \$100 billion. It is estimated that by 2050 more than 14 million Americans will live with the disease. There are over 28 new drugs for Alzheimer's disease in development, but more basic research is needed to keep the pipeline for new drugs robust. Inadequate funding could delay, prevent, and improve the treatment of the disease.
- Heart disease and stroke are the number one and three killers of Americans, respectively. Cardiovascular disease costs the United States more than \$350 billion annually. Since 1970, death rates from cardiovascular disease have fallen by 50 percent, but still remain the leading cause of death. Statin drugs that reduce cholesterol help to prevent heart disease and stroke, decrease recurrence of heart attacks and improve survival rates for heart transplant patients.
- Cancer is the second leading cause of death in the United States. The NIH estimates that the annual cost of the disease is over \$228 billion. NIH research has shown that human papillomavirus (HPV) vaccines protect against persistent infection by the two types of HPV that cause approximately 70 percent of cervical cancers. NIH funded researchers are using nanotechnology to develop probes that could pinpoint the location of tumors and deliver drugs directly to cancer cells.

NIH-funded studies have also indicated that adopting intensive lifestyle changes delayed onset of type-2 diabetes by 58 percent, and that progesterone therapy can reduce premature births by 30 percent in at-risk women. Historically, our past investment in basic biological research has led to many innovative medicines. The National Research Council reported that of the 21 drugs with the highest therapeutic impact, only five were developed without input from the public sector. The significant past investment in the NIH has provided major gains in our knowledge of the human genome, resulting in the promise of pharmacogenomics and a reduction in adverse drug reactions that currently represent a major worldwide health concern. Already, there are several examples where complete human genome sequence analysis has pinpointed disease-causing variants that have led to improved therapy and cures. Although the costs for such analyses have been reduced dramatically by technology improvements, widespread use of this approach will require further improvements in technology that will be delayed or obstructed with inadequate NIH funding.

Unless NIH can maintain an adequate funding stream, scientific opportunities will be delayed, lost, or forfeited to other countries. This investment in NIH also will directly support jobs for U.S. citizens and residents and help to stimulate the economy.

Investing in NIH Helps America Compete Economically

A \$35 billion budget in fiscal year 2012 will also help the NIH train the next generation of scientists. This investment will help to create jobs and promote economic growth.

Worldwide, other nations continue to invest aggressively in science. China has grown its science portfolio with annual increases to the research and development budget averaging over 23 percent annually since 2000. And while Great Britain has imposed strict austerity measures to address that Nation's debt problems, the Brit-

ish conservative party had the foresight to keep its strategic investments in science at current levels. Investment in research and development as a percentage of gross domestic product has remained static for the United States in the first decade of the 21st century, while growing by nearly 60 percent in China and 34 percent in South Korea.

NIH research funding helps to catalyze private sector growth. More than 83 percent of NIH funding is awarded to over 3,000 universities, medical schools, teaching hospitals and other research institutions in every State. NIH also helps form the key scientific foundations for the pharmaceutical and biotechnology industries.

Inadequate funding for NIH means more than a loss of scientific potential and discovery. Failing to help meet the NIH's scientific potential will mean a significant reduction in research grants, the resulting phasing-out of high quality research programs and jobs lost.

Conclusion

ASPET has full awareness for the many competing and important priorities facing the subcommittee. However, NIH and the biomedical research enterprise face a critical moment and the agency's contribution to the economic and physical well being of American's health should make it one of the Nation's top priorities. With enhanced and sustained funding, NIH has the potential to address many of the more promising scientific opportunities that currently challenge medicine. A \$35 billion fiscal year 2012 NIH budget will allow the agency to begin moving forward again to prevent, diagnose and treat disease, restoring the NIH to its role as a national treasure that attracts and retains the best and brightest to biomedical research, and providing hope to millions of individuals afflicted with illness and disease.

PREPARED STATEMENT OF THE AMERICAN SOCIETY OF NEPHROLOGY

Introduction

The American Society of Nephrology (ASN) thank you for the opportunity to submit a statement for the record to the Senate Appropriations Subcommittee on Labor, Health and Human Services, Education, and Related Agencies (LHHS Subcommittee). ASN urges the LHHS subcommittee to support robust funding for medical research in the fiscal year 2012 Federal budget.

ASN is a not-for-profit professional society of more than 11,000 scientists and physicians dedicated to cutting-edge medical research and delivering the highest quality therapies to patients. Foremost among ASN's concerns is the continued support of basic, translational, and clinical nephrology research.

The society's statement focuses on those issues and programs that most immediately fall under the committee's jurisdiction and assist our members in finding breakthrough treatments and cures for patients with kidney disease. We want to express our strong support for advancing programs supported by the National Institutes of Health (NIH) and the Agency for Healthcare Research and Quality (AHRQ). The ASN thanks the Subcommittee for its steadfast support of these programs and requests continued support of medical research in fiscal year 2012.

The Face of Kidney Disease

Chronic kidney disease now is a major public health problem in the United States, with as many as one in nine Americans or 26 million people suffering from kidney disease of some degree. This number is projected to rise, underscoring that support of medical research into the causes and treatments of kidney disease is essential to protecting public health. A growing population, a significant and growing cohort of Americans above age 65, the combined epidemics of cardiovascular disease, diabetes, and hypertension all lead to an increasing number of Americans with chronic kidney disease.

Chronic kidney disease affects people regardless of age, race, sex, socio economic background, or geographic location. It is estimated that at least 15 million people suffer from CKD, meaning that they have lost at least 50 percent of their kidney function. Most don't know it. Another 20 million more Americans are at increased risk of developing kidney disease. Again, most are unaware. Hypertension and diabetes are leading causes of kidney disease, with diabetes accounting for 44 percent of new cases of complete kidney failure. With both diabetes and hypertension on the rise, the need for additional kidney disease research takes on greater importance.

Kidney disease is also a major risk factor for cardiovascular disease, with half of patients with kidney failure dying from cardiovascular disease. Research at NIH continues to disentangle the relationship between kidney disease, cardiovascular disease, diabetes and hypertension.

Without treatment chronic kidney disease often progresses to complete kidney failure also known as end stage renal disease (ESRD), or permanent kidney failure. Patients with ESRD require dialysis or transplantation to survive for which Medicare covers the cost for almost all patients. Nearly 500,000 Americans have ESRD, and that continues to grow. Additionally, African-Americans, Native Americans, and Hispanics are at greater risk of developing ESRD than Caucasians. NIH research is helping to unlock the reasons behind these health disparities.

Economics Costs

Although no dollar amount can be affixed to human suffering or the loss of human life, economic data can help to identify and quantify the current and projected future financial costs associated with ESRD. The annual average cost per ESRD patient on dialysis is approximately \$71,000. This major cost to Medicare highlights the need to investigate new, and better apply, recently proven strategies for preventing and slowing the progress of kidney disease.

In short, we can treat and maintain patients who are at risk for losing their kidney function but the critical need is to prevent the loss of kidney function and its complications in the first place. Meeting this vital goal can only be accomplished through more concerted research and education.

Kidney Disease Research

National Institutes of Health (NIH)

NIH research is vital to the public and economic health of the United States. As such, ASN supports the Administration's program level request of \$31.987 billion for NIH in fiscal year 2012. Recognizing the economic challenges of the country's current fiscal situation, ASN nonetheless submits that maintaining level funding for NIH is imperative to the future health and well-being of the Nation. Research supported by NIH helps discover new cures and treatments for the millions of Americans with kidney disease and improves the lives of patients across the country. Medical research funded through NIH means hope for patients with kidney disease.

NIH research also serves as a vital economic engine. More than 80 percent of NIH funding flows back to States, maintaining jobs and promoting economic vitality. Support for NIH research helps ensure that the United States remains the world leader in cutting edge treatments for chronic disease. NIH grants and research fund the cures of tomorrow, and also fund researchers who form the backbone of our global competitiveness in the medical field. A drop in funding, even one that is short lived could have drastic consequences for the future research workforce.

In fiscal year 2012 an NIH budget of \$31.987 billion will allow research funding to keep pace with inflation, sustain the invaluable research projects currently underway, and allow the research workforce to remain adequately supported and protect a valuable investment in human talent.

Agency for Health Care Research and Quality (AHRQ)

Complementing the medical research conducted at NIH, AHRQ sponsors health services research designed to improve the quality of healthcare, decrease healthcare costs, and provide access to essential healthcare services by translating research into measurable improvements in the healthcare system. AHRQ supports emerging critical issues in healthcare delivery and addresses the particular needs of at risk populations. ASN firmly believes in the value of AHRQ's research and quality agenda, which continues to provide healthcare providers, policymakers, and patients with critical information needed to improve healthcare and treatment of chronic conditions such as kidney disease. As such ASN supports the Administration's budget request of \$366 million for AHRQ in fiscal year 2012.

Conclusion

The progression of chronic kidney disease to kidney failure can be slowed, with further research, treatments for stopping progression or even reversing it can be envisioned. Meanwhile, millions of Americans face a gradual decline in their quality of life because of kidney disease. Treatments of kidney failure including transplantation increase the ability of patients to be productive citizens. In many cases, abnormalities associated with early stage chronic renal disease remain undetected and are not diagnosed until the late stages. Chronic kidney disease requires our serious and immediate attention.

Medical research undertaken at NIH and AHRQ is essential to the health of patients with kidney disease, both present and future. As such, ASN urges the Subcommittee to adopt level funding for these programs in fiscal year 2012.

Thank you for your continued support for medical research and kidney disease. The society appreciates the opportunity to submit written testimony in support of

NIH and AHRQ. To discuss this written testimony, ASN, medical research or kidney disease, please contact ASN Director of Policy and Public Affairs Paul Smedberg.

PREPARED STATEMENT OF THE AMERICAN SOCIETY OF PLANT BIOLOGISTS

On behalf of the American Society of Plant Biologists (ASPB) we would like to thank the Subcommittee for its support of the National Institutes of Health (NIH).

ASPB and its members recognize the difficult fiscal environment our Nation faces, but believe investments in scientific research will be a critical step toward economic recovery. ASPB asks that the Subcommittee Members encourage increased support for plant biology research within NIH, which has contributed in innumerable ways to improving the lives of people throughout the world.

The American Society of Plant Biologists is an organization of approximately 5,000 professional plant biology researchers, educators, graduate students, and postdoctoral scientists with members in all 50 States and throughout the world. A strong voice for the global plant science community, our mission—achieved through work in the realms of research, education, and public policy—is to promote the growth and development of plant biology, to encourage and communicate research in plant biology, and to promote the interests and growth of plant scientists in general.

Plant Biology Research and America's Future

Plants are vital to our very existence. They harvest sunlight, converting it to chemical energy for food and feed; they take up carbon dioxide and produce oxygen; and they are the primary producers on which all life depends. Indeed, plant biology research is making many fundamental contributions in the areas of domestic fuel security and environmental stewardship; the continued and sustainable development of better foods, fabrics, pharmaceuticals, and building materials; and in the understanding of basic biological principles that underpin improvements in the health and nutrition of all Americans. In fact, the 2009 National Research Council (NRC) report *A New Biology for the 21st Century* placed plant biology at the center of urgent priorities in energy, food, health, and the environment.

For example, because plants are the ultimate source of both human nutrition and nutrition for domestic animals, plant biology has the potential to contribute greatly to reducing healthcare costs as well as playing an integral role in discovery of new drugs and therapies. Although the National Institutes of Health does offer some funding support to plant biology research, additional support would enable plant biologists to offer much more to advance the missions of the National Institutes of Health.

The importance of disciplinary and agency integration is a central theme of several recent NRC reports including *A New Biology for the 21st Century*, *Research at the Intersection of the Physical and Life Sciences*, and *Inspired by Biology: From Molecules to Materials to Machines*. ASPB encourages NIH to continue and expand its partnerships with other Federal science agencies—including the National Science Foundation, Department of Agriculture and Department of Energy—in advancing understanding about living systems that has application to a range of areas including human health.

Plant Biology and the National Institutes of Health

The mission of the NIH is to pursue “fundamental knowledge about the nature and behavior of living systems and the application of that knowledge to extend healthy life and reduce the burdens of illness and disability.” Plant biology research is highly relevant to this mission.

Plants are often the ideal model systems to advance our “fundamental knowledge about the nature and behavior of living systems,” as they provide the context of multi-cellularity while affording ease of genetic manipulation, a lesser regulatory burden, and inexpensive maintenance requirements than the use of animal systems. Many basic biological components and mechanisms are shared by both plants and animals. For example, a molecule named cryptochrome that senses light was identified first in plants and subsequently found to also function in humans, where it plays a central role in regulating our biological clock. Several human genetic disorders are linked to the malfunctioning of this clock—not to mention the effect of jet lag. As another example, some fungal pathogens can infect both humans and plants, and the molecular mechanisms employed by both the pathogen and its targeted host can be very similar.

More recently, a property known as RNA interface was first noted in plants; plant biologists trying to increase the color intensity of petunias by introducing a gene inducing pigment production instead observed a loss of color. RNA interface, which

has potential application in the treatment of human disease, was further elucidated in other plants and animals and earned two American scientists—Andrew Fire and Craig Mello—the 2006 Nobel Prize in Physiology or Medicine.

Health and Nutrition

Plant biology research is also central to the application of basic knowledge to “extend healthy life and reduce the burdens of illness and disability.” This connection is most obvious in the inter-related areas of nutrition and clinical medicine. Without good nutrition, there cannot be good health. Indeed, one World Health Organization study on childhood nutrition in developing countries concluded that over 50 percent of the deaths of children less than 5 years of age could be attributed to malnutrition’s effects in exacerbating common illnesses such as respiratory infections and diarrhea. Strikingly, most of these deaths were not linked to severe malnutrition but only to mild or moderate nutritional deficiencies. Plant biology researchers are working today to improve the nutritional content of crop plants by, for example, increasing the availability of nutrients and vitamins such as iron, vitamin E, and vitamin A. (Up to 500,000 children in the developing world go blind every year as a result of vitamin A deficiency).

By contrast, obesity, cardiac disease, and cancer take a striking toll in the developed world. Among many plant biology initiatives relevant to these concerns are research to improve the lipid composition of plant fats and efforts to optimize concentrations of plant compounds that are known to have anti-carcinogenic properties, such as the glucosinolates found in broccoli and cabbage, and the lycopenes found in tomato. Beta-glucans from certain cereals reduce serum cholesterol and insulin demand in diabetics. And scientists are able to use the fundamental knowledge of protein structures to reduce non-nutritious compounds, increasing the density and quality of proteins in some grains. Ongoing development of crop varieties with tailored nutraceutical content is an important contribution that plant biologists are making toward realizing the goal of personalized medicine, especially personalized preventative medicine.

Drug Discovery

Plants are also fundamentally important as sources of both extant drugs and drug discovery leads. In fact, over 10 percent of the drugs considered by the World Health Organization to be “basic and essential” are still exclusively obtained from flowering plants. Some historical examples are quinine, which is derived from the bark of the cinchona tree and was the first highly effective anti-malarial drug; and the plant alkaloid morphine, which revolutionized the treatment of pain. These pharmaceuticals are still in use today.

A more recent example of the importance of plant-based pharmaceuticals is the anti-cancer drug taxol. The discovery of taxol came about through collaborative work involving scientists at the National Cancer Institute within NIH and plant biologists at the U.S. Department of Agriculture. The plant biologists collected a wide diversity of plant materials, which were then evaluated for anti-carcinogenic properties. It was found that the bark of the Pacific yew tree yielded one such compound, which was isolated and named taxol after the tree’s Latin name, *Taxus brevifolia*. Originally, taxol could only be obtained from the tree bark itself, but additional research led to the elucidation of its molecular structure and eventually to its chemical synthesis in the laboratory.

On the basis of a growing understanding of metabolic networks, plants will continue to be sources for the development of new medicines to help treat cancer and other ailments. Taxol is just one example of a plant secondary compound. Since plants produce an estimated 200,000 such compounds, they will continue to provide a fruitful source of new drug leads, particularly if collaborations such as the one described above can be fostered and funded. With additional research support, plant biologists can lead the way to developing new medicines and biomedical applications to enhance the treatment of devastating diseases.

Conclusion

Despite the fact that plant biology research underlies so many vital practical considerations for our country, the amount invested in understanding the basic function and mechanisms of plants is small when compared with broader impacts.

The NIH does recognize that plants are a vital component of its mission. However, because the boundaries of plant biology research are permeable and because information about plants integrates with many different disciplines that are highly relevant to NIH, ASPB hopes that the Subcommittee will provide direction to NIH to support additional plant biology research in order to help pioneer new discoveries and new methods in biomedical research.

Thank you for your consideration of our testimony on behalf of the American Society of Plant Biologists. Please do not hesitate to contact ASPB if we can be of any assistance in the future; ASPB Public Affairs Director Dr. Adam P. Fagen can be reached at 301-296-0898 (phone), 301-296-0899 (fax), or afagen@aspb.org.

PREPARED STATEMENT OF THE AMERICAN SOCIETY OF TROPICAL MEDICINE AND
HYGIENE

The American Society of Tropical Medicine and Hygiene—the principal professional membership organization representing, educating, and supporting scientists, physicians, clinicians, researchers, epidemiologists, and other health professionals dedicated to the prevention and control of tropical diseases—appreciates the opportunity to submit testimony to the Senate Labor, Health and Human Services, and Education Appropriations Subcommittee.

We understand the fiscal constraints we as a country are in and are sensitive to the job Congress must do. The benefits of U.S. investment in tropical diseases are not only humanitarian, they are diplomatic as well. With this in mind, we respectfully request that the Subcommittee fund the following agencies in the fiscal year 2012 LHHS Appropriations bill to allow them to maintain their current programs and research priorities while ensuring a continued U.S. Government investment in global health and tropical medicine research and development:

National Institutes of Health, specifically:

- Malaria and neglected tropical disease treatment, control, and research and development efforts within the National Institute of Allergy and Infectious Diseases;
- An expanded focus on the treatment, control, and research and development for new tools for diarrheal disease within the NIH; specifically the inclusion of enteric infections on the Research, Condition, and Disease Categorization (RCDC) process on the Research Portfolio Online Reporting Tools (RePORT) website; and,
- Research capacity development in countries where populations are at heightened risk for malaria, NTDs, and diarrheal diseases through the Fogarty International Center.

The Centers for Disease Control and Prevention, including:

- CDC global health programs such as the CDC malaria program and providing direct funding to the CDC for NTD and diarrheal disease work; and
- Preserving and funding the activities of the CDC Vector Borne Disease Program as they merge with the Emerging and Infectious Disease Program to protect the United States from new and emerging infections.

RETURN ON INVESTMENT OF U.S.-FUNDED RESEARCH

CDC and NIH play essential roles in research and development for tropical medicine and global health. Both agencies are at the forefront of the new science that leads to tools to combat malaria and NTDs. This research provides jobs for American researchers and an opportunity for the United States to be a leader in the fight against global disease, in addition to lifesaving new drugs and diagnostics to some of the poorest, most at-risk people in the world.

For example, in Illinois, where ASTMH is based, 57,000 people are employed in bioscience research, which includes global health research. Illinois receives over \$700 million in funding from NIH and over \$200 million from CDC.¹ New Jersey also has a high level of investment in health-related research and development, with over 211,000 jobs supported by global health, and an economic impact of more than \$60 billion on the State in 2009.² Small investments in global health and tropical medicine research and development can yield big returns for State economies and research institutions.

TROPICAL DISEASE

Most tropical diseases are prevalent in either sub-Saharan Africa, parts of Asia (including the Indian subcontinent), or Central and South America. Many of the world's developing nations are located in these areas; thus, tropical medicine tends to focus on diseases that impact the world's most impoverished individuals.

¹Research America, "Global Health R&D, A Smart Investment for Illinois," <http://www.researchamerica.org/uploads/ILGHeconomicsheet.pdf>.

²Research America, "Global Health R&D, A Smart Investment for New Jersey," <http://www.researchamerica.org/uploads/NewJerseyFactSheet.pdf>.

Malaria.—Malaria remains a global emergency affecting mostly poor women and children; it is an acute, sometimes fatal disease. Despite being treatable and preventable, malaria is one of the leading causes of death and disease worldwide. Approximately every 30 seconds, a child dies of malaria—a total of about 800,000 under the age of 5 every year. The World Health Organization estimates that one half of the world's people are at risk for malaria and that there are 108 malaria-endemic countries. Additionally, WHO has estimated that malaria reduces sub-Saharan Africa's economic growth by up to 1.3 percent per year.

Neglected Tropical Diseases, also known as Diseases of Poverty.—NTDs are a group of chronic parasitic diseases, such as hookworm, elephantiasis, schistosomiasis, and river blindness, which represent the most common infections of the world's poorest people. These infections have been revealed as the stealth reason why the “bottom billion”—the 1.4 billion poorest people living below the poverty line—cannot escape poverty, because of the effects of these diseases on reducing child growth, cognition and intellect, and worker productivity.

Diarrheal disease.—The child death toll due to diarrheal illnesses exceeds that of AIDS, tuberculosis, and malaria combined. In poor countries, diarrheal disease is second only to pneumonia as the cause of death among children under 5 years old. Every week, 31,000 children in low-income countries die from diarrheal diseases.

The United States has a long history of leading the fight against tropical diseases that cause human suffering and pose financial burden that can negatively impact a country's economic and political stability. Tropical diseases, many of them neglected for decades, impact U.S. citizens working or traveling overseas, as well as our military personnel. Furthermore, some of the agents responsible for these diseases can be introduced and become established in the United States (like West Nile virus), or might even be weaponized.

NATIONAL INSTITUTES OF HEALTH

National Institute of Allergy and Infectious Diseases.—A long-term investment is critical to achieve the drugs, diagnostics, and research capacity needed to control malaria and NTDs. NIAID, the lead institute for malaria research, plays an important role in developing the drugs and vaccines needed to fight malaria. The NIH, through NIAID, also conducts research to better understand NTDs, through its own basic and clinical studies as well as extramural research.

ASTMH encourages the subcommittee to:

- Increase funding for NIH to expand the agency's investment in malaria, NTD, diarrheal disease research and to coordinate that work with other government agencies to maximize resources and ensure development of basic discoveries into usable solutions;
- Specifically invest in NIAID to support its role at the forefront of these efforts to developing the next generation of drugs, vaccines, and other interventions; and,
- Urge NIH to include enteric infections and neglected diseases in its RCDC process on the RePORT website to outline the work that is being done in these important research areas.

Fogarty International Center (FIC).—Biomedical research has provided major advances in the treatment and prevention of malaria, NTDs, and other infectious diseases. These benefits, however, are often slow to reach the people who need them most. FIC plays a critical role in strengthening science and public health research institutions in low-income countries. FIC works to strengthen research capacity in countries where populations are particularly vulnerable to threats posed by malaria, NTDs, and other infectious disease. This maximizes the impact of U.S. investments and is critical to fighting malaria and other tropical diseases.

ASTMH encourages the subcommittee to:

- Allocate sufficient resources to FIC in fiscal year 2012 to increase these efforts, particularly as they address the control and treatment of malaria, NTDs and diarrheal disease.

THE CENTERS FOR DISEASE CONTROL AND PREVENTION

Malaria Efforts.—Malaria has been eliminated as an endemic threat in the United States for over fifty years and CDC remains on the cutting edge of global efforts to reduce the toll of this deadly disease. CDC efforts on malaria fall into three broad categories: prevention, treatment, and monitoring/evaluation of efforts. The agency performs a wide range of basic research within these categories, such as:

- Conducting research on antimalarial drug resistance to inform new strategies and prevention approaches;

- Assessing new monitoring, evaluation, and surveillance strategies;
- Conducting additional research on malaria vaccines, including field evaluations; and
- Developing innovative public health strategies for improving access to anti-malarial treatment and delaying the appearance of antimalarial drug resistance.

ASTMH encourages the subcommittee to:

- Fund a comprehensive approach to effective and efficient malaria control, including adequately funding the important contributions of CDC.

NTD Programs.—CDC currently receives zero dollars directly for NTD work; however this should be changed to allow for more comprehensive work to be done on NTDs at the CDC. CDC has a long history of working on NTDs and has provided much of the science that underlies the global policies and programs in existence today. This work is important to any global health initiative, as individuals are often infected with multiple NTDs simultaneously.

ASTMH encourages the subcommittee to:

- Provide direct funding to CDC to continue its work on NTDs; and
- Urge CDC to continue its monitoring, evaluation, and technical assistance in these areas as an underpinning of efforts to control and eliminate these diseases.

Vector-borne Disease Program (VBDP).—The President's fiscal year 2012 budget folds the CDC Vector Borne Disease Program into the newly configured Emerging and Zoonotic Infectious Diseases program at CDC. Through the VBDP, researchers are able to practice essential surveillance and monitoring activities that protect the United States from deadly infections before they reach our borders. The world is becoming increasingly smaller as international travel increases and new pathogens are introduced quickly into new environments. We have seen this with SARS, avian influenza, and now, dengue fever, in the United States. Arboviruses like dengue, and others, such as chikungunya, are a constant threat to travelers, and to Americans generally.

Dengue fever, a disease with increased risk for Americans as the weather warms and dengue cases increase, is an example of why it is imperative that CDC be able to continue its disease monitoring and surveillance activities to protect the country from new and emerging threats like dengue and other arboviruses. Dengue fever, a viral disease transmitted by the Aedes mosquito, recently reemerged as a threat to Americans, with documented cases in the Florida Keys. Dengue usually results in fever, headache, and chills, but hemorrhagic dengue fever can cause severe internal bleeding, loss of blood, and even death. Because the Aedes mosquito is urban dwelling and often breeds in areas of poor sanitation, dengue is a serious concern for poor residents of coastal, urban areas in Texas, Louisiana, Mississippi, Alabama, and Florida.

ASTMH encourages the subcommittee to:

- Ensure that CDC maintain these important activities by continuing CDC funding for VBDP activities and require the program receive at least their fiscal year 2010 level of funding.

CONCLUSION

Thank you for your attention to these important U.S. and global health matters. We know Congress and the American people face many challenges in choosing funding priorities, and we hope you will provide the requested fiscal year 2012 resources to those programs identified above that meet critical needs for Americans and people around the world. ASTMH appreciates the opportunity to share its expertise, and we thank you for your consideration of these requests that will help improve the lives of Americans and the global poor.

PREPARED STATEMENT OF THE AMERICAN THORACIC SOCIETY

SUMMARY: FUNDING RECOMMENDATIONS

[In millions of dollars]

	Amount
National Institutes of Health	35,000
National Heart, Lung and Blood Institute	3,514
National Institute of Allergy and Infectious Disease	5,395
National Institute of Environmental Health Sciences	779.4

SUMMARY: FUNDING RECOMMENDATIONS—Continued

[In millions of dollars]

	Amount
Fogarty International Center	78.4
National Institute of Nursing Research	163
Centers for Disease Control and Prevention	7,700
National Institute for Occupational Safety & Health	332.4
Asthma Programs	31
Div. of Tuberculosis Elimination	231
Office on Smoking and Health	330
National Sleep Awareness Roundtable (NSART)	1

The American Thoracic Society (ATS) is pleased to submit our recommendations for programs in the Labor Health and Human Services and Education Appropriations Subcommittee purview. Founded in 1905, the ATS is an international education and scientific society of 15,000 specialists focused on respiratory, critical care and sleep medicine.

Lung Disease in America

Diseases of breathing constitute the third leading cause of death in the United States, responsible for one of every seven deaths. Diseases affecting the respiratory (breathing) system include chronic obstructive pulmonary disease (COPD), lung cancer, tuberculosis, influenza, sleep disordered breathing, pediatric lung disorders, occupational lung disease, sarcoidosis, asthma, and critical illness. COPD is now the third leading cause of disease death. The number of people with asthma in the United States has surged over 150 percent since 1980 and the root causes of the disease are still not fully known.

Despite the rising lung disease burden, lung disease research is underfunded. In fiscal year 2010, lung disease research represented just 22.6 percent of the National Heart Lung and Blood Institute's (NHLBI) budget. Although COPD is the third leading cause of death in the United States, research funding for the disease is a small fraction of the money invested for the other three leading causes of death. In order to stem the devastating effects of lung disease, research funding must continue to grow.

National Institutes of Health

The NIH is the world's leader in groundbreaking biomedical health research into the prevention, treatment and cure of diseases such as lung cancer, COPD and tuberculosis. Eighty-five percent of the NIH budget is invested in U.S. communities through universities, medical schools, hospitals and innovative small businesses, creating jobs and economic productivity. The American Reinvestment Recovery Act (ARRA) has generated remarkable scientific innovation that is paving the way for medical advances to improve patient outcomes. Without a funding increase in fiscal year 2012 to sustain the research pipeline, the NIH will be forced to reduce the number of research grants funded, which will result in the halting of vital research into diseases affecting millions around the world. We ask the subcommittee to provide \$35 billion in funding for the NIH in fiscal year 2012.

Centers for Disease Control and Prevention

In order to ensure that health promotion and chronic disease prevention are given top priority in Federal funding, the ATS supports a funding level for the Centers for Disease Control and Prevention (CDC) that enables it to carry out its prevention mission, and ensure a translation of new research into effective State and local public health programs. We ask that the CDC budget be adjusted to reflect increased needs in chronic disease prevention, infectious disease control, including TB control to prevent the spread of drug-resistant TB, and occupational safety and health research and training. The ATS recommends a funding level of \$7.7 billion for the CDC in fiscal year 2012.

COPD

COPD is the third leading cause of death in the United States and the third leading cause of death worldwide, yet the disease remains relatively unknown to most Americans. COPD is the term used to describe the limitation in breathing due mainly to emphysema and chronic bronchitis. CDC estimates that 12 million patients have COPD; an additional 12 million Americans are unaware that they have this life threatening disease. In 2010, the estimated economic cost of lung disease in the

United States was \$186 billion, including \$117 billion in direct health expenditures and \$69 billion in indirect morbidity and mortality costs.

Despite the growing burden of COPD, the United States does not currently have a comprehensive public health action plan on the disease. The ATS urges Congress to direct the NHLBI to develop a national action plan on COPD, in coordination with the Centers for Disease Control and Prevention (CDC) to expand COPD surveillance, development of public health interventions and research on the disease and increase public awareness of the disease. The NHLBI has shown successful leadership in educating the public about COPD through the COPD Education and Prevention Program.

CDC has an additional role to play in this work. We urge CDC to include COPD-based questions to future CDC health surveys, including the National Health and Nutrition Evaluation Survey (NHANES), the National Health Information Survey (NHIS) and the Behavioral Risk Factor Surveillance Survey (BRFSS).

Tobacco Control

Cigarette smoking is the leading preventable cause of death in the United States, responsible for one in five deaths annually. The ATS is pleased that the Department of Health and Human Services has made tobacco use prevention a key priority. The CDC's Office of Smoking and Health coordinates public health efforts to reduce tobacco use. In order to significantly reduce tobacco use within 5 years, as recommended by the subcommittee in fiscal year 2010, the ATS recommends a total funding level of \$330 million for the Office of Smoking and Health in fiscal year 2012, which includes an allocation of \$220 million from the Prevention and Public Health Fund.

Pediatric Lung Disease

The ATS is pleased to report that infant death rates for various lung diseases have declined for the past 10 years. In 2007, of the 10 leading causes of infant mortality, 4 were lung diseases or had a lung disease component. Many of the precursors of adult respiratory disease start in childhood. It is estimated that close to 22 million people suffer from asthma, including an estimated 7.1 million children. The ATS encourages the NHLBI to continue with its research efforts to study lung development and pediatric lung diseases.

Asthma

Asthma is a significant public health problem in the United States. Approximately 23 million Americans currently have asthma, including 7.1 million children. In 2009, 3,445 Americans in 2009 died as a result of asthma exacerbations. Asthma is the third leading cause of hospitalization among children under the age of 15 and is a leading cause of school absences from chronic disease. The disease costs our healthcare system over \$50.1 billion per year. African Americans have the highest asthma prevalence of any racial/ethnic group.

The President's fiscal year 2012 budget request proposes to merge the CDC's National Asthma Control Program with the Healthy Homes/Lead Poisoning Prevention Program and recommends funding cuts to the combined programs of over 50 percent. The ATS is deeply concerned that this proposal would drastically reduce States' capacity to implement a proven public health response to this disease. Asthma public health interventions are cost-effective. A study published in the American Journal of Respiratory Critical Care recently found that for every dollar invested in asthma interventions, there was a \$36 benefit. We urge the subcommittee to ensure that CDC's National Asthma Control Program remains a stand-alone program and receives an appropriation of \$31 million for fiscal year 2012.

Sleep

Several research studies demonstrate that sleep-disordered breathing and sleep-related illnesses affect an estimated 50–70 million Americans. The public health impact of sleep illnesses and sleep disordered breathing is still being determined, but is known to include increased mortality, traffic accidents, lost work and school productivity, cardiovascular disease, obesity, mental health disorders, and other sleep-related comorbidities. Despite the increased need for study in this area, research on sleep and sleep-related disorders has been underfunded. The ATS recommends a funding level of \$1 million in fiscal year 2012 to support activities related to sleep and sleep disorders at the CDC, including for the National Sleep Awareness Roundtable (NSART), surveillance activities, and public educational activities. The ATS also recommends an increase of funding for research on sleep disorders at the National Center for Sleep Disordered Research (NCSDR) at the NHLBI.

Tuberculosis

Tuberculosis (TB) is the second leading global infectious disease killer, claiming 1.7 million lives each year. It is estimated that 9–12 million Americans have latent tuberculosis. Drug-resistant TB poses a particular challenge to domestic TB control due to the high costs of treatment and intensive healthcare resources required. The global TB pandemic and spread of drug resistant TB presents a persistent public health threat to the United States.

Despite declining rates, persistent challenges to TB control in the United States remain. Specifically: (1) racial and ethnic minorities continue to suffer from TB more than majority populations; (2) foreign-born persons are adversely impacted; (3) sporadic outbreaks occur, outstripping local capacity; (4) continued emergence of drug resistance; and (5) there are critical needs for new diagnostics, treatment and prevention tools.

The Comprehensive Tuberculosis Elimination Act (CTEA, Public Law 110–392), enacted in 2008, reauthorized programs at CDC with the goal of putting the United States back on the path to eliminating TB. The ATS, recommends a funding level of \$231 million in fiscal year 2012 for CDC's Division of TB Elimination, as authorized under the CTEA, and encourages the NIH to expand efforts, as requested under the CTEA, to develop new tools to reduce the rising global TB burden.

Critical Illness

The burden associated with the provision of care to critically ill patients is anticipated to increase significantly as the population ages. Approximately 200,000 people in the United States require hospitalization in an intensive care unit because they develop a form of pulmonary disease called Acute Lung Injury. Despite the best available treatments, 75,000 of these individuals die each year from this disease. Investigation into diagnosis, treatment and outcomes in critically ill patients should be a high priority, and the NIH should be encouraged and funded to coordinate investigation related to critical illness in order to meet this growing national imperative.

Fogarty International Center

The Fogarty International Center (FIC) at NIH provides training grants to U.S. universities to teach AIDS treatment and research techniques to international physicians and researchers. Because of the link between AIDS and TB infection, FIC has created supplemental TB training grants for these institutions to train international health professionals in TB treatment and research. The ATS recommends Congress provide \$78.4 million for FIC in fiscal year 2012, to allow expansion of the TB training grant program from a supplemental grant to an open competition grant.

Researching and Preventing Occupational Lung Disease

The National Institute of Occupational Safety and Health (NIOSH) is the sole Federal agency responsible for conducting research and making recommendations for the prevention of work-related diseases and injury. The ATS recommends that Congress provide \$364.3 million in fiscal year 2012 for NIOSH to expand or establish the following activities: the National Occupational Research Agenda (NORA); tracking systems for identifying and responding to hazardous exposures and risks in the workplace; emergency preparedness and response activities; and training medical professionals in the diagnosis and treatment of occupational illness and injury.

Conclusion

Lung disease is a growing problem in the United States. The level of support this subcommittee approves for lung disease programs should reflect the urgency illustrated by these numbers. The ATS appreciates the opportunity to submit this statement to the subcommittee.

PREPARED STATEMENT OF THE AMERICANS FOR NURSING SHORTAGE RELIEF

The undersigned organizations of the ANSR Alliance greatly appreciate the opportunity to submit written testimony regarding fiscal year 2012 appropriations for the Title VIII Nursing Workforce Development Programs at the Health Resources and Services Administration (HRSA) and the Nurse Managed Health Clinics as authorized under Title III of the Public Health Service Act. We represent a diverse cross-section of healthcare and other related organizations, healthcare providers, and supporters of nursing issues that have united to address the national nursing shortage. ANSR stands ready to work with Congress to advance programs and policy that will ensure our Nation has a sufficient and adequately prepared nursing workforce to

provide quality care to all well into the 21st century. The Alliance, therefore, urges Congress to:

- Appropriate \$313 million in funding for Nursing Workforce Development Programs under Title VIII of the Public Health Service Act at the Health Resources and Services Administration (HRSA) in fiscal year 2012.
- Appropriate \$20 million in fiscal year 2012 for the Nurse Managed Health Clinics as authorized under Title III of the Public Health Service Act.

The Nursing Shortage

Nursing is the largest healthcare profession in the United States. According to the National Council of State Boards of Nursing, there were nearly 3.780 million licensed RNs in 2009. Nurses and advanced practice nurses (nurse practitioners, nurse midwives, clinical nurse specialists, and certified registered nurse anesthetists) work in a variety of settings, including primary care, public health, long-term care, surgical care facilities, and hospitals. The March 2008 study, *The Future of the Nursing Workforce in the United States: Data, Trends, and Implications*, calculates a projected demand of 500,000 full-time equivalent registered nurses by 2025. According to the U.S. Bureau of Labor Statistics, employment of registered nurses is expected to grow by 22 percent from 2008 to 2018, much faster than the average for all occupations and, because the occupation is very large, 581,500 new jobs will result. Based on these scenarios, the shortage presents an extremely serious challenge in the delivery of high quality, cost-effective services, as the Nation looks to reform the current healthcare system. Even considering only the smaller projection of vacancies, this shortage still results in a critical gap in nursing service, essentially three times the 2001 nursing shortage.

The Desperate Need for Nurse Faculty

Nursing vacancies exist throughout the entire healthcare system, including long-term care, home care and public health. Even the Department of Veterans Affairs, the largest sole employer of RNs in the United States, has a nursing vacancy rate of 10 percent. In 2006, the American Hospital Association reported that hospitals needed 116,000 more RNs to fill immediate vacancies, and that this 8.1 percent vacancy rate affects hospitals' ability to provide patient care. Government estimates indicate that this situation only promises to worsen due to an insufficient supply of individuals matriculating in nursing schools, an aging existing workforce, and the inadequate availability of nursing faculty to educate and train the next generation of nurses. At the exact same time that the nursing shortage is expected to worsen, the baby boom generation is aging and the number of individuals with serious, life-threatening, and chronic conditions requiring nursing care will increase. Consequently, more must be done today by the government to help ensure an adequate nursing workforce for the patients/clients of today and tomorrow.

A particular focus on securing and retaining adequate numbers of faculty is essential to ensure that all individuals interested in—and qualified for—nursing school can matriculate in the year that they are accepted. The National League for Nursing found that in the 2009–2010 academic year,

- 42 percent of qualified applications to prelicensure RN programs were turned away.
- One in four (25.1 percent) of prelicensure RN programs turned away qualified applicants.
- Four out of five (60 percent) of prelicensure RN programs were considered “highly selective” by national college admissions standards, accepting less than 50 percent of applications for admission.

Aside from having a limited number of faculty, nursing programs struggle to provide space for clinical laboratories and to secure a sufficient number of clinical training sites at healthcare facilities.

ANSR supports the need for sustained attention on the efficacy and performance of existing and proposed programs to improve nursing practices and strengthen the nursing workforce. The support of research and evaluation studies that test models of nursing practice and workforce development is integral to advancing healthcare for all in America. Investments in research and evaluation studies have a direct effect on the caliber of nursing care. Our collective goal of improving the quality of patient care, reducing costs, and efficiently delivering appropriate healthcare to those in need is served best by aggressive nursing research and performance and impact evaluation at the program level.

The Nursing Supply Impacts the Nation's Health and Economic Safety

Nurses make a difference in the lives of patients from disease prevention and management to education to responding to emergencies. Chronic diseases, such as heart disease, stroke, cancer, and diabetes, are the most preventable of all health

problems as well as the most costly. Nearly half of Americans suffer from one or more chronic conditions and chronic disease accounts for 70 percent of all deaths. In addition, increased rates of obesity and chronic disease are the primary cause of disability and diminished quality of life.

Even though America spends more than \$2 trillion annually on healthcare—more than any other nation in the world—tens of millions of Americans suffer every day from preventable diseases like type 2 diabetes, heart disease, and some forms of cancer that rob them of their health and quality of life. In addition, major vulnerabilities remain in our emergency preparedness to respond to natural, technological and manmade hazards. An October 2008 report issued by Trust for America's Health, entitled "Blueprint for a Healthier America," found that the health and safety of Americans depend on the next generation of professionals in public health. Further, existing efforts to recruit and retain the public health workforce are insufficient. New policies and incentives must be created to make public service careers in public health an attractive professional path, especially for the emerging workforce and those changing careers.

The Institute of Medicine report, *Hospital-Based Emergency Care: At the Breaking Point*, notes that nursing shortages in U.S. hospitals continue to disrupt hospitals operations and are detrimental to patient care and safety. Hospitals and other healthcare facilities across the country are vulnerable to mass casualty incidents themselves and/or in emergency and disaster preparedness situations. As in the public health sector, a mass casualty incident occurs as a result of an event where sudden and high patient volume exceeds the facilities resources. Such events may include the more commonly realized multi-car pile-ups, train crashes, hazardous material exposure in a building or within a community, high occupancy catastrophic fires, or the extraordinary events such as pandemics, weather-related disasters, and intentional catastrophic acts of violence.

Since 80 percent of disaster victims present at the emergency department, nurses as first receivers are an important aspect of the public health system as well as the healthcare system in general. The nursing shortage has a significant adverse impact on the ability of communities to respond to health emergencies, including natural, technological and manmade hazards.

Summary

The link between healthcare and our Nation's economic security and global competitiveness is undeniable. Having a sufficient nursing workforce to meet the demands of a highly diverse and aging population is an essential component to reforming the healthcare system as well as improving the health status of the Nation and reducing healthcare costs. To mitigate the immediate effect of the nursing shortage and to address all of these policy areas, ANSR requests \$313 million in funding for Nursing Workforce Development Programs under Title VIII of the Public Health Service Act at HRSA and \$20 million for the Nurse Managed Health Clinics under Title III of the Public Health Service Act in fiscal year 2012.

LIST OF ANSR MEMBER ORGANIZATIONS

Academy of Medical-Surgical Nurses	Emergency Nurses Association
American Academy of Ambulatory Care Nursing	Infusion Nurses Society
American Association of Critical-Care Nurses	International Nurses Society on Addictions
American Association of Nurse Assessment Coordinators	National Association of Clinical Nurse Specialists
American Organization of Nurse Executives	National Association of Hispanic Nurses
American Society for Pain Management Nursing	National Association of Nurse Practitioners in Women's Health
American Society of PeriAnesthesia Nurses	National Council of State Boards of Nursing
Association for Radiologic & Imaging Nursing	National Council of Women's Organizations
Association of Community Health Nursing Educators	National League for Nursing
Association of Pediatric Hematology/Oncology Nurses	National Nursing Centers Consortium
	National Student Nurses' Association, Inc.
	Nurses Organization of Veterans Affairs
	Society of Trauma Nurses

PREPARED STATEMENT OF THE ARTHRITIS FOUNDATION

The Arthritis Foundation greatly appreciates the opportunity to submit testimony in support of increased investment for arthritis research, prevention and programs at the Centers for Disease Control and Prevention (CDC); National Institutes of Health (NIH); Agency for Healthcare Research and Quality (AHRQ); and for the Health Resources and Services Administration (HRSA).

Arthritis is a complex family of musculoskeletal disorders with many causes, not yet fully understood, and so far there are no cures. It consists of more than 100 different diseases or conditions that destroy joints, bones, muscles, cartilage and other connective tissue which hampers or halts physical movement. Arthritis is one of the most prevalent chronic health problems and the most common cause of disability in the United States. 50 million people (1 in 5 adults) and almost 300,000 children live with the pain of arthritis every day. Arthritis limits the daily activities of 21 million Americans and accounts for \$128 billion annually in economic costs, including \$81 billion in direct costs for physician visits and surgical interventions and \$47 billion in indirect costs for missed work days. Counter to public perception, two-thirds of the people with doctor-diagnosed arthritis are under the age of 65. The pain, cost and disability associated with arthritis is simply unacceptable.

By the year 2030, an estimated 67 million or 25 percent of the projected adult population will have arthritis. Furthermore, arthritis limits the ability of people to effectively manage other chronic diseases. More than 57 percent of adults with heart disease and more than 52 percent of adults with diabetes also have arthritis. The Arthritis Foundation strongly believes that in order to prevent or delay arthritis from disabling people and diminishing their quality of life that a significant investment in proven prevention and intervention strategies is essential.

The following items summarize the Arthritis Foundation fiscal year 2012 funding recommendations for health agencies under the Subcommittee's jurisdiction.

Centers for Disease Control and Prevention

The Arthritis Foundation recommends a level of \$7.7 billion for CDC's core programs in fiscal year 2012. This amount is representative of what CDC needs to fulfill its core public health mission in fiscal year 2012; activities and programs that are essential to protect the health of the American people. CDC continues to be faced with unprecedented challenges and responsibilities, ranging from chronic disease prevention, eliminating health disparities, bioterrorism preparedness, to combating the obesity epidemic. More than 70 percent of CDC's budget actually flows out to States and local health organizations and academic institutions, many of which are currently struggling to meet growing needs with fewer resources.

The President's fiscal year 2012 budget request proposed to collapse existing programs for the top five leading chronic disease causes of death and disability—arthritis, cancer, diabetes, and heart disease and stroke—into a single State Block Grant program along with State funding for public health activities related to nutrition, physical activity, obesity and school health. These Administration proposals also rely on funding from the Prevention and Public Health Fund to support these activities.

In light of the fiscal challenges facing the Nation and the need to reduce inefficiencies from Federal program overlap and lack of coordination, the Arthritis Foundation recognizes that the CDC must combat chronic disease through careful coordination and collaboration across strategic programs. However, at the same time, agency leadership must ensure that the vital public health infrastructure that has been developed over the past two decades for combating arthritis should not be dismantled.

The clear need to ensure that the burgeoning number of Americans with arthritis are served by effective efforts, lead the Arthritis Foundation to conclude that, as proposed, the Administration's consolidated chronic disease prevention program is not in the best interest of those with arthritis. To sustain and build on the achievements and progress made to date in combating arthritis, it is critical that arthritis-specific activities are preserved and strengthened in any approach to combating chronic disease.

As the fiscal year 2012 funding process continues, the Arthritis Foundation appreciates the opportunity to evaluate any consolidated chronic disease program proposal to ensure that the following priorities are addressed:

- Programs should be designed around similar target populations, including people with or at risk of arthritis, the Nation's most common cause of disability and a major barrier to physical activity.
- Any consolidation must be limited to programs with clear programmatic and operational overlap.

- CDC and states must retain staff expertise in disease areas and the infrastructure to support them;
- Programs must be supported by State-based advisory groups made up of stakeholders from the impacted disease areas;
- A national advisory committee at CDC should be created to foster stakeholder involvement from arthritis and other chronic disease communities.

The CDC's arthritis program received \$13.1 million in fiscal year 2011 funding and about half of that amount will be distributed via competitive grant to 12 States. Research shows that the pain and disability of arthritis can be decreased through early diagnosis and appropriate management, including evidence-based self-management activities that enable weight control and physical activity. The Arthritis Foundation's Self-Help Program, a group education program, has been proven to reduce arthritis pain by 20 percent and physician visits by 40 percent. These evidence-based interventions are recognized by the CDC to reduce the pain of arthritis and importantly reduce healthcare expenditures through a reduction in physician visits. For arthritis prevention to grow to include another 12–15 States an investment of an additional \$10 million is required.

National Institutes of Health/National Institute of Arthritis and Musculoskeletal and Skin Diseases

The Arthritis Foundation supports \$35 billion in fiscal year 2012 for NIH to invest in improving the health and quality of life for all Americans. NIH-funded research drives scientific innovation and develops new and better diagnostics, improved prevention strategies, and more effective treatments. Approximately 83 percent of appropriated funds for NIH research are sent to every State in the Nation in the form of merit based peer review grants. These investigator initiated grants enable the highest quality of research to be conducted at research facilities and hospitals all across the Nation employing hundreds of thousands of individuals and representing an integral part of hundreds of local communities. Congress should recognize the unique role NIH plays as the economic engine in the biomedical industry.

NIH-funded research has led to new treatments, which have greatly improved the quality of life for people living with arthritis; however, the ultimate goal is to find a cure. The Arthritis Foundation firmly believes research holds the key to tomorrow's advances and provides hope for a future free from arthritis pain. As one of the largest non-profit contributors to arthritis research, the Arthritis Foundation fills a vital role in the big picture of arthritis research. Our research program complements government and industry-based arthritis research by focusing on training new investigators and pursuing innovative strategies for preventing, controlling and curing arthritis.

The mission of the NIH/National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS) is to support research into the causes, treatment, and prevention of arthritis and musculoskeletal and skin diseases and the training of basic and clinical scientists to carry out this research. Research opportunities at NIAMS are being curtailed due to the stagnating and in some cases declining numbers of new grants being awarded. The training of new investigators has unnecessarily slowed down and contributed to a crisis in the research community where new investigators have begun to leave biomedical research careers. The Arthritis Foundation urges Congress to prioritize NIAMS funding to address the Nation's most chronic, disabling and costly diseases.

Last year, scientists supported by the National Institutes of Health developed a technique that led to the successful re-growth of damaged leg joints in animals. The accomplishment shows that it's possible to lure the body's own cells to injured regions and generate new tissues, such as cartilage and bone. The finding could point the way toward joint renewal in humans, which could be a dramatic and less costly alternative to the 1 million joint replacement surgeries each year.

Juvenile arthritis afflicts 300,000 children in the United States and when left untreated, it can cause permanent damage to joints and tissues throughout the body. Juvenile arthritis has serious consequences that can limit a young person's ability to grow properly, learn, and become a productive citizen in the workforce. With a dire critical shortage of pediatric rheumatologists to treat these children, it is vital that the NIH and NIAMS continue supporting a national network of cooperating clinical centers for the care and study of children with arthritis through the Childhood Arthritis and Rheumatology Research Alliance (CARRA). This NIH funded project is in the beginning stages of collecting data from the largest group of children with juvenile rheumatic diseases nationwide. The data will be available to pediatric rheumatologists throughout the United States. The collection and distribution of such disease data are crucial to the understanding of the progression of juvenile arthritis and specific outcomes related to treatment. NIH must continue to fund

this invaluable resource to improve the outcomes and lives of children with juvenile arthritis as is currently done for children with cancer. The Arthritis Foundation has also invested our research dollars in this CARRA initiative.

Public investment in biomedical research holds the real promise of improving the lives of millions of Americans with arthritis. An investment in NIH funded research is an investment in our Nation's future.

Health Resources and Services Administration

The Arthritis Foundation strongly recommends funding a loan repayment program for pediatric specialist at the \$30 million level within HRSA for fiscal year 2012. A pediatric loan repayment program was authorized by Congress in 2010 (in the Affordable Care Act) and requires funding to commence. HRSA is essential to developing the healthcare workforce that is so critical in primary care as well as shortages in specialty care, like pediatric rheumatology.

Juvenile arthritis is the leading cause of acquired disability in children and is the sixth most common childhood disease. Sustaining the field of pediatric rheumatology is essential to the care of the almost 300,000 children under the age of 18 living with a form of juvenile arthritis. Children who are diagnosed with juvenile arthritis will live with this chronic and potentially disabling disease for their entire life. Therefore, it is imperative that children are diagnosed quickly and start treatment before significant irreversible joint damage is done. However, it is a challenge to first find a pediatric rheumatologist, as nine States do not have a single one, and then to have a timely appointment as many States have only one or two to see thousands of patients. Pediatric rheumatology is one of the smallest pediatric subspecialties with less than 200 pediatric rheumatologists actively practicing in the United States. A report to Congress in 2007 stated there was a 75 percent shortage of pediatric rheumatologists and recommended loan repayment program to help address this critical workforce shortage issue. The Affordable Care Act included authorizing HRSA \$30 million to establish a loan repayment program for pediatric specialists including pediatric rheumatologists. The Arthritis Foundation strongly recommends the Subcommittee provide an initial appropriation to begin this critical program.

Agency for Healthcare Research and Quality (AHRQ)

The Arthritis Foundation recommends an overall funding level of \$405 million for AHRQ in fiscal year 2012. AHRQ funds research and programs at local universities, hospitals, and health departments that improve healthcare quality, enhance consumer choice, advance patient safety, improve efficiency, reduce medical errors, and broaden access to essential services. Specifically, the science funded by AHRQ provides consumers and their healthcare professionals with valuable evidence to make the right healthcare decisions for themselves and their families.

The Arthritis Foundation appreciates the opportunity to submit our recommendations for fiscal year 2012 to Congress on behalf of the 50 million adults and 300,000 children with arthritis and looks forward to working with the Subcommittee in the coming months.

PREPARED STATEMENT OF ASME INTERNATIONAL

The NIH Task Force ("Task Force") of the ASME Bioengineering Division is pleased to provide comments on the bioengineering-related programs contained within the National Institutes of Health (NIH) fiscal year 2012 budget request. The Task Force is focused on the application of mechanical engineering knowledge, skills, and principles for the conception, design, development, analysis and operation of biomechanical systems.

The Importance of Bioengineering

Bioengineering is an interdisciplinary field that applies physical, chemical, and mathematical sciences, and engineering principles to the study of biology, medicine, behavior, and health. It advances knowledge from the molecular to the organ levels, and develops new and novel biologics, materials processes, implants, devices, and informatics approaches for the prevention, diagnosis, and treatment of disease, for patient rehabilitation, and for improving health. Bioengineers have employed mechanical engineering principles in the development of many life-saving and life-improving technologies, such as the artificial heart, prosthetic joints, diagnostics, and numerous rehabilitation technologies.

Background

The NIH is the world's largest organization dedicated to improving health through medical science. During the last 50 years, NIH has played a leading role in the major breakthroughs that have increased average life expectancy by 15 to 20 years.

The NIH is comprised of different Institutes and Centers that support a wide spectrum of research activities including basic research, disease and treatment-related studies, and epidemiological analyses. The mission of individual Institutes and Centers varies from either study of a particular organ (e.g. heart, kidney, eye), a given disease (e.g. cancer, infectious diseases, mental illness), a stage of life (e.g. childhood, old age), or finally it may encompass crosscutting needs (e.g., sequencing of the human genome). The National Institute of Biomedical Imaging and Bioengineering (NIBIB) focuses on the development, application, and acceleration of biomedical technologies to improve outcomes for a broad range of healthcare challenges.

Fiscal Year 2012 NIH Budget Request

The total fiscal year 2012 NIH budget request is \$31.98 billion, or 2.4 percent above the \$31.08 billion fiscal year 2010 appropriated amount and 4.1 percent above the \$30.7 billion provided for fiscal year 2011. The Task Force recognizes that this proposed increase is significant given the Administration's commitment to reducing the Federal deficit. However, the Task Force notes that the Administration's 2.4 percent increase to the overall NIH budget from fiscal year 2010 to fiscal year 2012 is less than the up to 3 percent projected increase in medical research costs due to inflation for fiscal year 2012 alone—as predicted by the Biomedical Research and Development Price Index (BRDPI). This inflationary pressure is compounded with the \$30.7 billion appropriation for fiscal year 2011, a \$260 million or 0.8 percent reduction in funding from the previous fiscal year, and a BRDPI of 2.9 percent for fiscal year 2011, resulting in a significant decrease in funding for the NIH over fiscal year 2010 to fiscal year 2012.

NIH is enacting policies to guide investments while limiting the impact of these inflationary cost increases, including a 1 percent increase in the average cost of competing and non-competing Research Project Grants (RPGs); a 1 percent increase in Research Centers and Other Research; and a 1 percent increase for Intramural Research and Research Management and Support; and constraints on staffing levels. However, these policies alone are not sufficient to offset the need for additional support for critical areas of health research, especially given reduction in funding and high inflation rate for fiscal year 2011. We therefore fully support the President's proposed fiscal year 2012 budget level for the NIH given current budget constraints, but further recommend out-year budget increases well beyond BRDPI inflation rates.

The Task Force further notes that NIH received \$10.4 billion as part of the American Recovery and Reinvestment Act (ARRA) of 2009 (Public Law 111–5), an important influx for several key divisions of NIH over the fiscal year 2009 and fiscal year 2010 funding cycles, particularly the NIBIB, which received \$78 million—less than 1 percent of the \$10.4 billion ARRA budget assigned to the NIH for the fiscal year 2009 and fiscal year 2010 funding cycles. NIBIB has already exhausted this budget, leaving no additional ARRA funding to leverage through the fiscal year 2011 budget cycle and underscoring the need for more robust investment in bioengineering at NIBIB. While this one-time influx of funding for health research and infrastructure was justified, the Task Force notes that the unstable nature of such funding inhibits the potential impact on the economy and should not be viewed as a viable substitute for steady and consistent support from Congress for these critical national research priorities.

The Administration estimates 9,158 Research Project Grants (RPG) will be supported under the fiscal year 2012 budget for NIH-wide RPGs. From fiscal year 2010 to fiscal year 2011, inflationary pressures and budget factors combined to result in a decrease of 652 in the number of competing RPGs. The Task Force commends the Administration for again focusing on funding RPGs in fiscal year 2012, resulting in an increase of 424 supported grants over the fiscal year 2011 level of competing RPGs. We reiterate again however, that the number of RPGs supported from fiscal year 2010 to fiscal year 2012 will still decline by 228 under this austere fiscal year 2012 budget scenario.

NIBIB Research Funding

The Administration's fiscal year 2012 budget request supports \$322 million for the NIBIB, an increase of \$5.6 million or 1.8 percent from the fiscal year 2010 appropriated amount. The mission of the NIBIB is to seek to improve human health by leading the development and application of emerging and breakthrough tech-

nologies based on a merging of the biological, physical, and engineering sciences. As noted above, this increase is well under the 3 percent projected increase in research costs due to inflation (predicted by the BRDPI index) and, as a consequence, actually results in an effective decrease in funding for NIBIB compared to fiscal year 2010.

The budget for NIBIB Research Grants would remain flat at \$262.7 million. Funding for intramural research would increase 7.3 percent to \$11.8 million from \$11 million in fiscal year 2010. NIBIB's Research Management and Support request is \$175.3 million, a 3 percent increase over fiscal year 2010.

NIBIB funds the Applied Science and Technology (AST) program, which supports the development and application of innovative technologies, methods, products, and devices for research and clinical application that transform the practice of medicine. The fiscal year 2012 request for AST is \$170.6 million, a \$2.2 million increase or 1.3 percent increase from fiscal year 2010.

Additionally, NIBIB funds the Discover Science and Technology (DST) program, which is focused on the discovery of innovative biomedical engineering and imaging principles for the benefit of public health. The fiscal year 2011 request for DST is \$95.3 million, a \$1.2 million or 1.3 percent increase from fiscal year 2010.

The Technological Competitiveness-Bridging the Sciences program, which funds interdisciplinary approaches to research, would receive \$25.9 million in fiscal year 2012, a \$0.9 million increase or 3.6 percent over the fiscal year 2010 enacted level.

Task Force Recommendations

The Task Force is concerned that the United States faces rapidly growing challenges from our counterparts in the European Union and Asia with regards to bioengineering advancements. While total health-related U.S. research and development investments have expanded significantly over the last decade, investment in bioengineering at NIBIB have remained relatively flat over the last several years. In fact, the fiscal year 2012 budget actually represents a small reduction in funding when the fiscal year 2003 NIBIB appropriation of \$280 million is adjusted for inflation—\$329 million in 2010 dollars—leaving NIBIB with an effective reduction in funding of \$7 million since 2003.

The Task Force wishes to emphasize that, in many instances, bioengineering-based solutions to healthcare problems can result in improved health outcomes and reductions in healthcare costs. For example, coronary stent implantation procedures cost approximately \$20,000, compared to bypass graft surgery at double the cost. Stenting involves materials science (metals and polymers), mechanical design, computational mechanical modeling, imaging technologies, etc. that bioengineers work to develop. Not only is the procedure less costly, but the patient can return to normal function within a few days rather than months to recover from bypass surgery, greatly reducing other costs to the economy. Therefore, we strongly urge Congress to consider increased funding for bioengineering within the NIBIB and across NIH, and work to strengthen these investments in the long run to reduce U.S. healthcare costs and support continued U.S. leadership in bioengineering.

Even during these challenging fiscal times, the NIBIB must obtain sustained funding increases, both to accelerate medical advancements as our Nation's population ages, and to mirror the growth taking place in the bioengineering field. The Task Force believes that the Administration's budget request for fiscal year 2012 is not aligned with the long-term challenges posed by this objective; a 1.8 percent budget increase will not keep up with current inflationary increases for biomedical research, eroding the United States' ability to lay the groundwork for the medical advancements of tomorrow.

While the Task Force supports Federal proposals that seek to double Federal research and development in the physical sciences over the next decade, we believe that strong Federal support for bioengineering and the life sciences is essential to the health and competitiveness of the United States. The supplemental funding that NIH received as part of ARRA and the budget request by the Administration does not erase the past several years of disappointing budgets. Congress and the Administration should work to develop a specific plan, beyond President Obama's call for "innovations in healthcare technology" to focus on specific and attainable medical and biomedical research priorities which will reduce the costs of healthcare and improve healthcare outcomes. Further, Congress and the Administration should include in this strategy new mechanisms for partnerships between NSF and the NIH to promote bioengineering research and education. The Task Force feels these initiatives are necessary to build capacity in the U.S. bioengineering workforce and improve the competitiveness of the U.S. bioengineering research community.

PREPARED STATEMENT OF THE ASSOCIATION FOR PROFESSIONALS IN INFECTION CONTROL AND EPIDEMIOLOGY (APIC) AND THE SOCIETY FOR HEALTHCARE EPIDEMIOLOGY OF AMERICA (SHEA)

The Association for Professionals in Infection Control and Epidemiology (APIC) and The Society for Healthcare Epidemiology of America (SHEA) thank you for this opportunity to submit testimony on Federal efforts to eliminate healthcare-associated infections (HAIs).

APIC's mission is to improve health and patient safety by reducing the risk of HAIs and related adverse outcomes. The organization's more than 14,000 members, known as infection preventionists, direct infection prevention and control programs that save lives and improve the bottom line for hospitals and other healthcare facilities throughout the United States and around the globe. Our association strives to promote a culture within healthcare institutions where all members of the healthcare team fully embrace the elimination of HAIs. We advance these efforts through education, research, collaboration, practice guidance, public policy, and support for credentialing.

SHEA was founded in 1980 to advance the application of the science of healthcare epidemiology. The Society works to achieve the highest quality of patient care and healthcare personnel safety in all healthcare settings by applying epidemiologic principles and prevention strategies to a wide range of quality-of-care issues. SHEA is a growing organization, strengthened by its membership in all branches of medicine, public health, and healthcare epidemiology. SHEA and its members are committed to implementing evidence-based strategies to prevent HAIs. SHEA members have scientific expertise in evaluating potential strategies for eliminating preventable HAIs.

APIC and SHEA collaborate with a wide range of infection prevention and infectious diseases societies, specialty medical societies in other fields, quality improvement organizations, and patient safety organizations in order to identify and disseminate evidence-based practices. The Centers for Disease Control and Prevention (CDC), its Division of Healthcare Quality Promotion (DHQP) and the Federal Healthcare Infection Control Practices Advisory Committee (HICPAC), and the Council of State and Territorial Epidemiologists (CSTE) have been invaluable Federal partners in the development of guidelines for the prevention and control of HAIs and in their support of translational research designed to bring evidence-based practices to patient care. Further, collaboration between experts in the field (epidemiologists and infection preventionists), the CDC and the Agency for Healthcare Research and Quality (AHRQ) plays a critical role in defining and prioritizing the research agenda. In 2008, APIC and SHEA aligned with The Joint Commission and the American Hospital Association to produce and promote the implementation of evidence-based recommendations in the Compendium of Strategies to Prevent Healthcare-Associated Infections in Acute Care Hospitals (<http://www.shea-online.org/about/compendium.cfm>). APIC and SHEA also contribute expert scientific advice to quality improvement organizations such as the Institute for Healthcare Improvement (IHI), the National Quality Forum (NQF), and State-based task forces focused on infection prevention and public reporting issues.

HAIs are among the leading causes of preventable death in the United States, accounting for an estimated 1.7 million infections and 99,000 associated deaths in 2002. In addition to the substantial human suffering caused by HAIs, these infections contribute \$28 billion to \$33 billion in excess healthcare costs each year.

The good news is that some of these infections are on the decline. In particular, bloodstream infections associated with indwelling central venous catheters, or "central lines," are largely preventable when healthcare providers use the CDC infection prevention recommendations in the context of a performance improvement collaborative. Healthcare professionals have reduced these infections in hospital intensive care unit (ICU) patients by 58 percent since 2001, which represents up to 27,000 lives saved. In spite of this notable progress, there is a great deal of work to be done to achieve the goal of HAI elimination. These additional opportunities to save lives and improve patient safety involve settings outside ICUs and those patients who need hemodialysis.

To build and then sustain these winnable battles against HAIs, we urge you, in fiscal year 2012, to support the CDC Coalition's request for \$7.7 billion for the CDC's "core programs." Within that broader area, the CDC is currently involved in a number of projects that have allowed for significant progress to be made in reducing HAIs. In light of this important work, we ask that you provide the CDC with its requested amount of \$47.4 million for HAI prevention activities.

Included among these activities is support for State-based programs to expand facility enrollment in the CDC's National Healthcare Safety Network (NHSN), an im-

portant reporting and monitoring tool that enables officials to track where HAIs are occurring and identify where improvements need to be made. NHSN's data analysis function helps our members analyze facility-specific data and compare rates to national metrics. Importantly, the patients we serve throughout the United States have established expectations that reported reductions in the frequency of HAIs are accurate. APIC and SHEA have, through their respective networks of members, identified limitations in other measures of performance. These studies have consistently identified that data from the CDC's NHSN provides a more precise picture of performance relative to reduction of HAIs. Many States consider NHSN to be the best option for implementing standardized reporting of HAI data. The CDC has also been supporting research networks to address important scientific gaps in HAI prevention, improvement in HAI tracking and monitoring methodologies, as well as responding to requests for assistance from health departments and healthcare facilities. It is vital to ensure that the NHSN meets these expectations from patients and that our successes are real and tangible improvements in the care provided.

In addition, we request that the Subcommittee provide \$50 million for antimicrobial resistance activities. As the CDC states in its request, "repeated and improper uses of antibiotics are important factors in the increase in drug-resistant bacteria, viruses, and parasites," and "preventing infections and decreasing inappropriate antibiotic use are the best strategies to control resistance." Ensuring the effectiveness of antibiotics well into the future is vital for the nation's public health. It is essential, therefore, that the CDC maintains the ability to monitor organism resistance in healthcare and promote appropriate antibiotic use. This has become even more critical due to two recent developments. First, pharmaceutical manufacturers have largely abandoned development of newer antibiotics because there are several market-based disincentives to investing in this research and development. Second, there is an epidemic of infections caused by *Clostridium difficile*, a bacterium that is triggered by use of antibiotics. These infections are widespread, disproportionately affect older adults, and can be fatal. There are several examples in the scientific literature that demonstrate the rate of *C. difficile* infections drops in facilities with active, effective antimicrobial stewardship programs.

We also support the Administration's \$5 million request for HAI activities. This funding will allow HHS, under the HHS Action Plan to Prevent Healthcare-Associated Infections (HAI Action Plan), to prioritize recommended clinical practices, strengthen data systems, and develop and launch a nationwide HAI prevention campaign. APIC and SHEA members have been engaged in this partnership for HAI prevention under the leadership of HHS Assistant Secretary for Health, Dr. Howard Koh and Deputy Assistant Secretary for Healthcare Quality, Dr. Don Wright.

We believe the development of the HAI Action Plan and the funding to support these activities has been critical to the effort to build support for a coordinated Federal plan and message on preventing infections. Additionally, we strongly believe that the CDC has the necessary expertise to define appropriate metrics through which the HAI Action Plan can best measure its efforts.

APIC and SHEA also request that the Subcommittee approve \$10.7 million for the Centers for Medicare and Medicaid Services (CMS) surveys of ambulatory surgical centers (ASCs) as part of the budget request addressing direct survey costs. CMS's survey process, jointly developed with the CDC in this case, consists of targeting infection control deficiencies in ASCs with a frequency of every 4 years. Due to the increasing number of surgeries performed in outpatient settings, and the need to ensure that basic infection prevention practices are followed, APIC believes continuation of this survey tool is essential. This support will also protect patients' lives as there have been several outbreaks in ASCs involving transmission of bloodborne pathogens, such as hepatitis C, due to unsafe practices.

Also within the direct survey costs portion of CMS's request, the agency indicates plans to launch an HAI pilot program as part of the HHS HAI strategic plan. This promises to produce a significant amount of feedback on HAI prevention as CMS intends to survey critical access hospitals and smaller hospitals across 10 to 25 States. This will allow officials to gather information from facilities whose practices and data have not traditionally been monitored or widely shared.

APIC and SHEA are pleased with the Administration's continued support of biomedical research by providing an increase of almost \$32 billion for the National Institutes of Health (NIH) in fiscal year 2012, a 2.4 percent increase over fiscal year 2010 levels. The NIH is the single largest funding source for infectious diseases research in the United States and the life-source for many academic research centers. The NIH-funded work conducted at these centers lays the ground work for advancements in treatments, cures, and medical technologies. It is critical that we maintain this momentum for medical research capacity.

Unfortunately, support for basic, translational, and epidemiological HAI research has not been a priority of the NIH. Despite the fact that HAIs are among the top ten annual causes of death in the United States, scientists studying these infections have received relatively less funding than colleagues in many other disciplines. In 2008, NIH estimated that it spent more than \$2.9 billion on funding for HIV/AIDS research, approximately \$2 billion on cardiovascular disease research, and about \$664 million on obesity research. By comparison, the National Institute of Allergy and Infectious Diseases (NIAID) provided \$18 million for MRSA research. APIC and SHEA believe that as the magnitude of the HAI problem becomes an increasing part of our public health dialogue, it is imperative that the Congress and funding organizations put significant resources behind this momentum.

The limited availability of Federal funding to study HAIs has the effect of steering young investigators interested in pursuing research on HAIs toward other, better-funded fields. While industry funding is available, the potential conflicts of interest, particularly in the area of infection prevention technologies, make this option seriously problematic. These challenges are limiting professional interest in the field and hampering the clinical research enterprise at a time when it should be expanding.

Our field is faced with the need to bundle, implement and adhere to interventions we believe to be successful while simultaneously conducting basic, epidemiological, pathogenetic and translational studies that are needed to move our discipline to the next level of evidence-based patient safety. The current convergence of scientific, public and legislative interest in reducing rates of HAIs can provide the necessary momentum to address and answer important questions in HAI research. APIC and SHEA strongly urge you to enhance NIH funding for fiscal year 2012 to ensure adequate support for the research foundation that holds the key to addressing the multifaceted challenges presented by HAIs.

Finally, we support the \$34 million in the Administration's fiscal year 2012 budget that would continue, and allow expansion of, funding for AHRQ grants related to HAI prevention in multiple healthcare settings, including surgical and dialysis centers. Infections are one of the leading causes of hospitalization and death for patients on hemodialysis. According to the CDC, approximately 37,000 bloodstream infections occurred in hemodialysis outpatients with central lines (2008). AHRQ's plans to broaden research support in ambulatory and long-term care settings to align with the HHS HAI Action Plan represent another positive step in addressing HAIs in a comprehensive fashion.

We thank you for the opportunity to submit testimony and greatly appreciate this Subcommittee's assistance in providing the necessary funding for the Federal Government to have a leadership role in the effort to eliminate HAIs.

PREPARED STATEMENT OF THE ASSOCIATION FOR RESEARCH IN VISION AND
OPHTHALMOLOGY

Congressional and Presidential support for biomedical research

In 2009, Congress spoke volumes in passing S. Res. 209 and H. Res. 366, which designated the years 2010 to 2020 as The Decade of Vision, in which the majority of 78 million Baby Boomers will face the greatest risk for aging eye disease. This decade is not the time for a less-than-inflationary increase for a community that lost 20.1 percent purchasing power over the course of the last 10 years.¹

As President Obama has stated repeatedly, most recently during the 2011 State of the Union Address, biomedical research reduces healthcare costs, increases productivity, and it ensures global competitiveness of the United States.

ARVO has two major requests for Senate:

—For Senate to budget NIH in fiscal year 2012 at \$35 billion.

This amount: Is a \$3 billion increase over the President's proposed budget; maintains NIH net funding levels from fiscal year 2009 and fiscal year 2010; and ensures that NIH can maintain funding for existing grants and award the same number of new grants.

—For Senate to make vision health a priority and fund NEI in fiscal year 2012 above the 1.8 percent increase over last year that was proposed by the President.

—We request this even if Congress does not fund NIH at \$35 billion.

¹ Calculations were based solely upon annual biomedical research and development price index (BRDPI) and annual appropriated amounts. Fiscal year 2011 funding levels and fiscal year 2011 BRDPI were not part of the calculation.

—Why? Investing in research is a short term investment, with a 2.2-fold economic return from innovation. It has a long term pay-off that can reduce healthcare spending on eye diseases that are increasing in aging populations and growing minority populations that have vision health disparities (e.g. glaucoma and diabetic retinopathy). The majority of research grant budgets pay for good paying positions. Very little of the budget goes towards supplies and equipment. It addresses one of American's greatest fears: fear of losing eye sight.

Grant review eliminates budget excess

ARVO stands behind member John Ash, Ph.D., who stated the following during January 2011 ARVO Advocacy Day visits to Capitol Hill: "We understand the need for budget cuts, but we should be cutting budgets similar to how U.S. citizens trim their household budgets, not across the board, but rather where there is waste and inefficiency. We challenge you to find another government agency that uses money more efficiently than the National Institutes of Health."

The strategic plan for NIH grant programs (for example, the NEI strategic plan) represents the collective vision of hundreds of scientists throughout the United States. Funding decisions for individual grant applications are awarded based on scientific merit and past progress. Specifically, experts review grant applications and assign scores based on the quality and impact of the proposed research. Scientific merit and funding decisions are based on applicant competitiveness among peers. An additional level of scrutiny and guidance is provided by an NEI program panel of experts, the National Advisory Eye Council. Progress on funded projects is monitored annually by NIH, and excess budgets are trimmed taking into consideration ongoing development of other projects. Thus, the process is highly competitive from conception of a project through completion.

Cost of vision impairment

Vision disorders are the fourth most prevalent disability in the United States and the most frequent cause of disability in children. NEI estimates that vision impairment and eye disease cost the United States \$68 billion annually. However, this number does not factor in the impact of indirect healthcare costs, lost productivity, reduced independence, diminished quality of life, increased depression, and accelerated mortality.

NEI's fiscal year 2010 baseline funding of \$707 million reflects just a little more than 1 percent of the annual costs of eye disease. The continuum of vision loss presents a major public health problem, as well as a significant financial challenge to the public and private sectors.

Prevention saves money long term

Seventy-seven percent of Americans agree that research is part of the solution to rising healthcare costs, and 84 percent understand that prevention and wellness reduce healthcare costs (Your Candidates-Your Health Poll, August 2010). Less-than-inflationary budget increases represent short term cost-cutting that will cost taxpayers more money in the long term. Prevention can save Medicare/Medicaid payments for vision care in the aging population and in minority populations with disproportionate incidence of eye disease (e.g. glaucoma and diabetic retinopathy). NEI funding is a vital investment in overall health and vision health of our Nation that prevents health expenditures. Maintaining vision allows people to remain independent and employed, reduces family burdens, and ultimately, improves the safety of individuals and the entire community (driving safety being a prime example).

Research is an economic investment

Merely 2 percent of Americans think research is not important to the U.S. economy (National Poll, May 2010). The largest portion of NIH grant budgets is for salaries distributed across the country, and many of the positions funded are for good paying jobs. The lower paying jobs are an investment in training the future biomedical research work force. To learn about the economic impact of research by state, visit http://www.researchamerica.org/economic_impact.

Vision research improves eye care

Below are three of the top vision success stories since 2003, as reported by nearly 400 U.S.-based ARVO members, who work at NEI-funded institutions. Examples come from responses to an ARVO survey about the NEI strategic plan. There were too many vision achievements to list them all.

Drug therapies for macular degeneration (AMD).—Vision researchers developed a therapy to treat the most aggressive form of AMD ("wet" AMD) that works much better than even hoped for. Not only is vision loss stopped, in many cases sight is

partially regained. The therapy is so successful that it is now being used for other eye complications (e.g., eye infections, injuries and diabetes). Furthermore, a National Eye Institute-funded clinical trial (Comparison of AMD Treatments Trial), comparing safety and effectiveness of two drugs to treat advanced AMD, shows that a \$50 drug (Avastin) is as effective as a \$2,000 drug (Lucentis). Since 250,000 patients are treated each year for AMD, this will reduce Medicare and other government health spending. <http://1.usa.gov/jZpZyv>

Gene therapies for eye disease.—Vision researchers developed gene therapies for three retinal diseases: Leber congenital amaurosis, color blindness and retinitis pigmentosa. They also identified important genetic risk factors for age-related eye diseases, including age-related macular degeneration and glaucoma. Critically, these discoveries are the first “pay-off” of any kind from the Human Genome Project for patients and taxpayers.

Cellular and molecular therapies.—Using regenerative medical approaches, vision researchers made important progress in repairing damaged eye tissues (e.g., cornea and retina). By repairing damaged tissues vision function is rescued.

Continued vision research needs

ARVO members expressed continued need for research support for the following areas (and many additional areas not covered here).

- Aging eye disease.*—Accelerate our efforts in basic and translational research to discover the causes of and new treatments for macular degeneration, diabetic retinopathy and other vision-robbing diseases whose risks of occurrence and severity increase with age.
- Children’s vision.*—Find noninvasive ways to detect vision problems in children early enough to start treatment before vision is lost or their education is affected.
- Brain and eye injury.*—Develop ways to rapidly seal wounds and trauma encountered by civilians and the military, so ocular and brain function can be maintained.
- Eye pain.*—Understand the basis of eye pain and develop therapies to treat it.
- Eye infections.*—Identify better ways to identify and treat drug-resistant eye-infections with antibiotics and anti-viral medications. Certain infections can destroy eye tissues in just 24 hours.
- Invest in shared therapeutic targets.*—Identify common, shared causes for common eye diseases and common systemic diseases. Establish meaningful collaborations between researchers, so shared therapeutic strategies may be developed that can treat multiple diseases.
- Identify at-risk groups and raise awareness.*—Support development of educational tools to raise awareness and treatment compliance in people in age groups or ethnic groups, who are more susceptible to certain eye diseases.
- Understand environmental factors that make it more likely to develop eye disease and educate people on how to prevent eye disease.*
- Eye surgery.*—Identify circumstances when the risk of performing eye surgery is greater than the benefit. Develop ways to treat sight problems without surgery, including facilitating natural wound healing.

Resources

Facts about State vision health: http://apps.nccd.cdc.gov/DDT_VHI/VHIHome.aspx.

Fact sheet about vision and blindness: <http://www.researchamerica.org/uploads/factsheet16vision.pdf>.

The Silver Book: Vision Loss. <http://www.eyerresearch.org/pdf/VisionLossSilverbook.pdf>.

About ARVO

ARVO is the world’s largest international association of vision scientists (scientists who study diseases and disorders of the eye). About 80 percent of members from the United States (>7,000 total) are supported by NIH grant funding. Vision science is a multi-disciplinary field, but the National Eye Institute is the only free-standing NIH institute with a mission statement that specifically addresses vision research. ARVO supports increased fiscal year 2011 and fiscal year 2012 NIH funding.

ARVO is also a member of the National Alliance for Eye and Vision Research, and supports their testimony. www.eyerresearch.org

PREPARED STATEMENT OF THE ASSOCIATION OF AMERICAN CANCER INSTITUTES

The Association of American Cancer Institutes (AACI), representing 94 of the Nation's premier academic and free-standing cancer centers, appreciates the opportunity to submit this statement for consideration by the United States Senate Subcommittee on Labor, Health and Human Services, Education and Related Agencies, Committee on Appropriations.

AACI thanks the administration, Congress and the Subcommittee for their long-standing commitment to ensuring quality care for cancer patients, as well as for providing researchers with the tools that they need to develop better cancer treatments and, ultimately, to cure this disease.

President Obama's fiscal year 2012 budget calls for \$31.829 billion for NIH. This is an increase of \$1.045 billion (3.4 percent) over the fiscal year 2010 comparable level of \$30.784 billion. The President's proposed budget for the National Cancer Institute would be increased by \$95 million, to \$5.2 billion.

Sustaining progress against cancer requires a Federal commitment to funding research through the NIH and NCI at a level that at least keeps pace with medical inflation. With that in mind, AACI is joining with its colleagues in the biomedical research community in supporting the proposed increases for NIH and NCI and in calling on Congress to further strengthen the impact of the President's request by increasing funding to \$35 billion for NIH and to \$5.9 billion for NCI. The requested increases account for lost funding due to discontinuation of the American Recovery and Reinvestment Act of 2009, and the ongoing shortfall in NIH and NCI funding in relation to annual changes in the Biomedical Research and Development Price Index (BRDPI), which indicates how much the NIH budget must change to maintain purchasing power.

Taking a closer look at the President's proposed fiscal year 2012 budget, as with so many complicated and vitally important matters, the devil is in the details. While the President's budget includes a proposed increase of \$95.31 million over fiscal year 2010 for NCI, the line item funding for Cooperative Clinical Research remains the same as fiscal year 2010—\$254.487 million. Other NCI line items show funding decreases, including Comprehensive/Specialized Cancer Centers (\$46.001 million decrease) and Research and Development Contracts (\$39.409 million decrease).

AACI and its members are acutely aware of the difficult fiscal environment that the country is facing. The vast majority of our cancer centers exist within universities that are undergoing drastic budget reductions and as a consequence, directors at our member cancer centers are already facing extreme budgetary challenges. Furthermore, many of our senior and most promising young investigators are now without NCI funding and are requiring significant bridge funding from private sources. In recent years, however, it has become more challenging to raise philanthropic and other external funds. As a result, we continue to be highly dependent on Federal cancer center grants.

Recent developments at one member center, the Nevada Cancer Institute (NVC), illustrate that need. Serving 15,000 patients since it opened in 2005, NVC has recently laid off half of its 300 employees. In a local news report, NVC officials cited a number of reasons for the layoffs, including a miserable economy that has hurt fundraising, a worsening reimbursement environment that provides less money from government and private insurance entities for services rendered, and fewer Federal grant dollars in the recession. ("Debt puts Nevada Cancer Institute on heels", Las Vegas Review-Journal, April 8, 2011.)

Cancer centers are already challenged to provide the infrastructure necessary to support funded researchers, and cuts in Federal grants will limit our ability to provide well functioning shared resources to investigators who depend on them to complete their research. For most matrix cancer centers, the majority of NCI grant funds are used to sustain the shared resources so essential to basic, translational, clinical and population cancer research, or to provide matching dollars which allow departments to recruit new cancer researchers to a university and support them until they receive their first grants.

As highlighted by NCI Director Harold Varmus in a January "town hall" meeting with NCI staff, independent investigator research is a particularly valuable resource, particularly in the area of genomics and molecular epidemiology. Such research is highly dependent on state-of-the-art shared resources like tissue processing and banking, DNA sequencing, microRNA platforms, proteomics, biostatistics and biomedical informatics. This infrastructure is expensive, and it is not clear where cancer centers would turn for alternative funding if NCI grant contributions to these efforts were reduced.

An investigator and medicinal chemist at a large AACI member center spent 7 years developing two new targeted drugs that are now in clinical trial testing. One

agent shows promise in cancers of the blood; the other against breast, colon, lung and prostate tumors. Research on these agents required advanced technologies provided by the center's shared resources, including analytical cell-sorting, microarray assays, and toxicopathological evaluations of mouse models, which are an essential part of drug discovery. If budget cuts had forced the closure of one or more of these shared resources, these new targeted therapies might never have made it to the patients who are now benefiting from them. The researcher has 8 to 10 more compounds in the pipeline, the fate of which hinges largely on the 2012 budget. Unfortunately, hundreds of other promising cancer researchers across the U.S. share this troubling uncertainty.

Cancer Research: Benefiting Americans' Health and Economic Well-being

Cancer's financial and personal impact on America is substantial and growing—one in two men and one in three women will face cancer in their lifetimes, and cancer cost our Nation more than \$228 billion in 2008 (Centers for Disease Control and Prevention, *Addressing The Cancer Burden: At A Glance* 2010).

The U.S. Centers for Disease Control & Prevention's latest report on cancer survivorship, "Cancer Survivors-United States, 2007", shows that the number of cancer survivors in the United States increased from 3 million in 1971 to 9.8 million in 2001 and 11.7 million in 2007—an increase from 1.5 percent to 4 percent of the U.S. population. Cancer survivors largely consist of people who are 65 years of age or older and women. More than a million people were alive in 2007 after being diagnosed with cancer 25 years or more earlier. Of the 11.7 million people living with cancer in 2007, 7 million were 65 years of age or older, 6.3 million were women, and 4.7 million were diagnosed 10 years earlier or more.

Investing in cancer research is a prudent step—both for the health of our Nation and for its economic well-being. Cancer research, conducted in academic laboratories across the country, saves money by reducing healthcare costs associated with the disease, enhances the United States' global competitiveness, and has a positive economic impact on localities that house a major research center.

In May 2011, AACI engaged Tripp Umbach, a research firm specializing in economic impact studies, to conduct an analysis of potential effects on statewide and national economic activity and employment resulting from NCI funding cuts to AACI cancer centers. Two reduced funding levels were considered: (1) a "conservative" 0.8 percent reduction, as implemented in the 2011 continuing resolution for the Federal budget, passed by Congress in March, and, (2) an "aggressive" 5.3 percent cut, reflecting an overall fiscal year 2012 budget reduction proposed by some members of Congress. This reduction would rollback NCI funding to 2008 levels. The impact of the 0.8 percent cut is already being felt: NCI announced on May 5 that it would need to cut funding for the NCI cancer centers program by 5 percent.

The report estimates that the total economic decline resulting from a 0.8 percent cut in NCI funding would result in a loss of at least \$84.5 million to the U.S. economy, with a 5.3 percent funding drop causing a \$564.7 million economic loss nationwide. The economic impact is even greater when overall NIH funding is considered. A 0.8 percent reduction in NIH funding would mean a \$530.8 million loss to the U.S. economy, with a 5.3 percent reduction leading to a \$3.5 billion loss.

Employment declines from the 0.8 percent NCI funding reduction would total at least 629 jobs while 4,200 jobs would be lost with a 5.3 percent funding cut. Applying the same calculations to total NIH appropriations would eliminate nearly 4,000 jobs based on the conservative reduction, increasing to 26,300 jobs lost with a 5.3 percent cut. It is important to note that research and health sciences jobs are generally high-paying and the loss of even a handful of such jobs can have a measurable effect on local economic activity.

While the economic aspects of cancer research are important, what cannot be overstated is the impact cancer research has had on individuals' lives—lives that have been lengthened and even saved by virtue of discoveries made in cancer research laboratories at cancer centers across the United States.

Biomedical research has provided Americans with better cancer treatments, as well as enhanced cancer screening and prevention efforts. Some of the most exciting breakthroughs in current cancer research are those in the field of personalized medicine. In personalized medicine for cancer, not only is the disease itself considered when determining treatments, but so is the individual's unique genetic code. This combination allows physicians to better identify those at risk for cancer, detect the disease, and treat the cancer in a targeted fashion that minimizes side effects and refines treatment in a way to provide the maximum benefit to the patient.

In the laboratory setting, multi-disciplinary teams of scientists are working together to understand the significance of the human genome in cancer. For instance, the Cancer Genetic Markers of Susceptibility initiative is comparing the DNA of

men and women with breast or prostate cancer with that of men and women without the diseases to better understand the diseases. The Cancer Genome Atlas is in development as a comprehensive catalog of genetic changes that occur in cancer.

Illustrating the successes realized by cancer research, NCI's most recent Annual Report to the Nation on the Status of Cancer reported that rates of death in the United States from all cancers for men and women continued to decline between 2003 and 2007, the most recent reporting period available. The report also finds that the overall rate of new cancer diagnoses for men and women combined decreased an average of slightly less than 1 percent per year for the same period.

Despite those improvements, "cancer disparities" abound, with different groups of cancer sufferers and cancer types showing little improvement or higher rates of incidence. For example, childhood cancer incidence rates (rates of new diagnoses) continued to increase while death rates in this age group decreased. Childhood cancer is classified as cancers occurring in those 19 years of age or younger. And there are several other forms of cancer (e.g. pancreatic, lung) and patient populations (racial and ethnic minorities, the poor, those with psychosocial issues) with high rates of cancer mortality and morbidity. Furthermore, with the increased incidence and survival comes higher morbidity because two-thirds of this surviving patient population experience late effects that are classified as serious to life-threatening.

The Nation's Cancer Centers

The nexus of cancer research in the United States is the Nation's network of cancer centers represented by AACI. These cancer centers conduct the highest-quality cancer research anywhere in the world and provide exceptional patient care. The Nation's research institutions, which house AACI's member cancer centers, receive an estimated \$3.71 billion from the National Cancer Institute (NCI) to conduct cancer research in fiscal year 2010; more than two-thirds of NCI's total budget (U.S. Department of Health and Human Services, National Institutes of Health, National Cancer Institute 2010 Fact Book). In fact, approximately 84 percent of NCI's budget supports research at nearly 650 universities, hospitals, cancer centers, and other institutions in all 50 States. Because these centers are networked nationally, opportunities for collaborations are many—assuring wise and non-duplicative investment of scarce Federal dollars.

In addition to conducting basic, clinical, and population research, the cancer centers are largely responsible for training the cancer workforce that will practice in the United States in the years to come. Much of this training depends on Federal dollars, via training grants and other funding from NCI. Sustained Federal support will significantly enhance the centers' ability to continue to train the next generation of cancer specialists—both researchers and providers of cancer care.

By providing access to a wide array of expertise and programs specializing in prevention, diagnosis, and treatment of cancer, cancer centers play an important role in reducing the burden of cancer in their communities. The majority of the clinical trials of new interventions for cancer are carried out at the nation's network of cancer centers.

Conclusion

These are exciting times in science and, particularly, in cancer research. The AACI cancer center network is unrivaled in its pursuit of excellence, and places the highest priority on affording all Americans access to superior cancer care, including novel treatments and clinical trials. It is through the power of collaborative innovation that we will accelerate progress toward a future without cancer, and research funding through the NIH and NCI is essential to achieving our goals.

PREPARED STATEMENT OF THE ASSOCIATION OF AMERICAN MEDICAL COLLEGES

The Association of American Medical Colleges (AAMC) is a not-for-profit association representing all 134 accredited U.S. and 17 accredited Canadian medical schools; nearly 400 major teaching hospitals and health systems; and nearly 90 academic and scientific societies. Through these institutions and organizations, the AAMC represents 128,000 faculty members, 75,000 medical students, and 110,000 resident physicians. The association appreciates the opportunity to address four programs that play critical roles in assisting medical schools and teaching hospitals to fulfill their missions of education, research, and patient care: the National Institutes of Health (NIH); the Agency for Healthcare Research and Quality (AHRQ); health professions education funding through the Health Resources and Services Administration (HRSA)'s Bureau of Health Professions; and the National Health Service Corps. The AAMC appreciates the Subcommittee's longstanding, bipartisan efforts to strengthen these programs.

National Institutes of Health.—The NIH is one of the Nation's greatest achievements. The Federal Government's unwavering support for medical research through the NIH has created a scientific enterprise that is the envy of the world and has contributed greatly to improving the health and well-being of all Americans—indeed of all humankind.

The AAMC is grateful to the Subcommittee for its efforts to prioritize NIH funding in fiscal year 2011 and supports the budget request of \$31.748 billion for NIH in fiscal year 2012. More than 83 percent of NIH research funding is awarded to more than 3,000 research institutions in every State; at least half of this funding supports life-saving research at America's medical schools and teaching hospitals. This successful partnership not only lays the foundation for improved health and quality of life, but also strengthens the Nation's long-term economy.

The foundation of scientific knowledge built through NIH-funded research drives medical innovation that improves health and quality of life through new and better diagnostics, improved prevention strategies, and more effective treatments. NIH research has contributed to dramatically increased and improved life expectancy over the past century. A baby born today can look forward to an average life span of nearly 78 years—almost three decades longer than a baby born in 1900, and life expectancy continues to increase. People are staying active longer, too: the proportion of older people with chronic disabilities dropped by nearly a third between 1982 and 2005. Thanks to insights from NIH-funded studies, the death rate for coronary heart disease is more than 60 percent lower—and the death rate for stroke, 70 percent lower—than in the World War II era.

For example, a new ability to comprehend the genetic mechanisms responsible for disease is already providing insights into diagnostics and identifying a new array of drug targets. We are entering an era of personalized medicine, where prevention, diagnosis, and treatment of disease can be individualized, instead of using the standardized approach that all too often wastes healthcare resources and potentially subjects patients to unnecessary and ineffective medical treatments and diagnostic procedures.

Peer-reviewed, investigator-initiated basic research is the heart of NIH research. These inquiries into the fundamental cellular, molecular, and genetic events of life are essential if we are to make real progress toward understanding and conquering disease. Additional funding is needed to sustain and enhance basic research activities, including increasing support for current researchers and promoting opportunities for new investigators and in those areas of biomedical science that historically have been underfunded.

The application of the results of basic research to the detection, diagnosis, treatment, and prevention of disease is the ultimate goal of medical research. Clinical research not only is the pathway for applying basic research findings, but it often provides important insights and leads to further basic research opportunities. The AAMC supports additional funding for the continued expansion of clinical research and clinical research training opportunities, including rigorous, targeted post-doctoral training; developmental support for new and junior investigators; and career support for established clinical investigators, especially to enable them to mentor new investigators.

Anecdotal evidence suggests that changes in healthcare delivery systems and other financial factors pose a serious threat to the research infrastructure of America's medical schools and teaching hospitals, particularly for clinical research. The AAMC supports efforts to enhance the research infrastructure, including resources for clinical and translational research; instrumentation and emerging technologies; and animal and other research models.

Among the areas NIH has identified as ripe for investment and integral to the health of the American people is enhancing the evidence base for healthcare decisions. NIH's long-standing investment in Comparative Effectiveness Research (CER) has informed the clinical guidelines that assist physicians and their patients in making better decisions about the most effective care. Knowledge from NIH-supported CER has changed the way diabetes, atrial fibrillation, hypertension, HIV/AIDS, schizophrenia, and many other conditions are treated. In addition to diagnostic and treatment trials, knowing more about the performance of disease prevention initiatives and medical care delivery will improve health.

The AAMC supports efforts to reinvigorate research training, including developing expanded medical research opportunities for minority and disadvantaged students. For example, the volume of data being generated by genomics research, as well as the increasing power and sophistication of computing assets on the researcher's lab bench, have created an urgent need, both in academic and industrial settings, for talented individuals well-trained in biology, computational technologies,

bioinformatics, and mathematics to realize the promise offered by modern interdisciplinary research.

The AAMC is heartened by the Administration's proposals to provide a four percent stipend increase for predoctoral and postdoctoral research trainees supported by NIH's Ruth L. Kirschstein National Research Service Awards program. These stipend increases are necessary if medical research is to remain an attractive career option for the brightest U.S. students. Attracting the most talented students and postdoctoral fellows is essential if the United States is to retain its position of world leadership in biomedical and behavioral research.

As Raymond Orbach, former Under Secretary for Science at the Department of Energy for President George W. Bush, noted in a recent editorial in *Science*, "Other countries, such as China and India, are increasing their funding of scientific research because they understand its critical role in spurring technological advances and other innovations. If the United States is to compete in the global economy, it too must continue to invest in research programs."

Agency for Healthcare Research and Quality.—Complementing the medical research supported by NIH, AHRQ sponsors health services research designed to improve the quality of healthcare, decrease healthcare costs, and provide access to essential healthcare services by translating research into measurable improvements in the healthcare system. The AAMC firmly believes in the value of health services research as the Nation continues to strive to provide high-quality, efficient, and cost-effective healthcare to all of its citizens. The AAMC joins the Friends of AHRQ in recommending \$405 million for the agency in fiscal year 2012.

As the lead Federal agency to improve healthcare quality, AHRQ's overall mission is to support research and disseminate information that improves the delivery of healthcare by identifying evidence-based medical practices and procedures. The Friends of AHRQ funding recommendation will allow AHRQ to continue to support patient-centered health research and other valuable research initiatives including strategies for translating the knowledge gained from patient-centered research into clinical practice, healthcare delivery, and provider and patient behaviors. These research findings will better guide and enhance consumer and clinical decisionmaking, provide improved healthcare services, and promote efficiency in the organization of public and private systems of healthcare delivery.

Health Professions Funding.—The Title VII and VIII health professions and nursing education programs are the only Federal programs designed to improve the supply, distribution, and diversity of the Nation's healthcare workforce. For almost 50 years, Title VII and Title VIII have provided education and training opportunities to a wide variety of aspiring healthcare professionals, both preparing them for careers in the health professions and helping bring healthcare services to our rural and underserved communities. Through loans, loan guarantees, and scholarships to students, and grants and contracts to academic institutions and non-profit organizations, the Title VII and Title VIII programs fill the gaps in the supply of health professionals not met by traditional market forces. The AAMC supports the fiscal year 2012 request of \$762.5 million for these important workforce programs in the upcoming fiscal year.

Since 1963, the Title VII and Title VIII education and training programs have helped the workforce adapt to the evolving healthcare needs of the ever-changing American population. In an effort to renew and update Titles VII and VIII to meet current workforce challenges, the programs were reauthorized in 2010—the first reauthorization in the past decade. Reauthorization not only improved the efficiency of the Title VII and Title VIII programs, but also laid the groundwork for innovative programs with an increased focus on recruiting and retaining professionals in underserved communities.

The AAMC appreciates the Subcommittee's longstanding support of the Title VII and Title VIII programs, as well as bipartisan recognition that a strong healthcare workforce is essential to the continued health and prosperity of the American people, particularly in the face of unprecedented existing and looming provider shortages. However, recognition alone will not solve the significant disparities between the needs of the American people and the number of providers willing and able to care for them. To ensure that the Nation's already fragile healthcare system is able to care for the expanding elderly population; meet the unique needs of the country's sick and ailing children and minority populations; and provide essential primary care services to the neediest amongst us, it is essential that Congress prioritize the healthcare workforce with a strong commitment to the Title VII and Title VIII health professions programs in fiscal year 2012.

In addition to funding for Title VII and Title VIII, HRSA's Bureau of Health Professions also supports the Children's Hospitals Graduate Medical Education program. This program provides critical Federal graduate medical education support

for children's hospitals to prepare the future primary care workforce for our Nation's children and for pediatric specialty care—the greatest workforce shortage in children's healthcare. The AAMC has serious concerns about the President's plan to eliminate support for this essential program in fiscal year 2012, as well as the \$48.5 million (15 percent) cut imposed on the program in fiscal year 2011. At a time when the Nation faces a critical doctor shortage and more Americans are about to enter the health insurance system, any cuts to funding that supports physician training will have serious repercussions for Americans' health. We strongly urge restoration to \$317.5 million in fiscal year 2012.

National Health Service Corps.—The AAMC lauds the commitment of the Affordable Care Act to address health professional workforce shortages by authorizing up to \$535.1 million for the NHSC in fiscal year 2012. The NHSC is widely recognized—both in Washington and in the underserved areas it helps—as a success on many fronts. It improves access to healthcare for the growing numbers of underserved Americans, provides incentives for practitioners to enter primary care, reduces the financial burden that the cost of health professions education places on new practitioners, and helps ensure access to health professions education for students from all backgrounds. Over its 39-year history, the NHSC has offered recruitment incentives, in the form of scholarship and loan repayment support, to more than 37,000 health professionals committed to serving the underserved.

In spite of the NHSC's success, demand for health professionals across the country remains high. At a field strength of 7,530 in fiscal year 2010, the NHSC fell over 24,000 practitioners short of fulfilling the need for primary care, dental, and mental health practitioners in Health Professions Shortage Areas (HPSAs), as estimate by HRSA. While the "American Recovery and Reinvestment Act of 2009" (Public Law 111-5) provided a temporary boost in annual awards, this increase must be sustained to help address the health professionals workforce shortage and growing maldistribution.

The AAMC supports the president's fiscal year 2012 budget request of \$124 million, which returns the NHSC to fiscal year 2008 discretionary levels. The president's budget also assumes that the NHSC has access to \$295 million in additional dedicated funding through the HHS Secretary's CHC Fund. This additional funding is necessary to sustain the increased NHSC field strength and help address current health professional workforce shortages. The AAMC further recommends that the Subcommittee include report language directing the Secretary to provide this enhanced funding for the NHSC over the fiscal year 2008 level, as directed under healthcare reform.

PREPARED STATEMENT OF THE ASSOCIATION OF AMERICAN VETERINARY MEDICAL COLLEGES

The Association of American Veterinary Medical Colleges (AAVMC) is pleased to submit this statement for the record in support of the fiscal year 2012 budget request of \$449.5 million for the health professions education programs authorized under Title VII of the Public Health Service Act and administered through the Health Resources and Services Administration (HRSA). AAVMC is also pleased to provide comments on the pending transfer of authorities of the National Center for Research Resources (NCRR) within the National Institutes of Health (NIH).

AAVMC provides leadership for and promotes excellence in academic veterinary medicine to prepare the veterinary workforce with the scientific knowledge and skills required to meet societal needs through the protection of animal health, the relief of animal suffering, the conservation of animal resources, the promotion of public health, and the advancement of medical knowledge. AAVMC provides leadership for the academic veterinary medical community, including in the United States all 28 colleges of veterinary medicine, nine departments of veterinary science, eight departments of comparative medicine, two other veterinary medical educational institutions; and internationally, all five veterinary medical colleges in Canada, eleven international colleges of veterinary medicine, and three international affiliate colleges of veterinary medicine.

The Title VII and VIII health professions and nursing programs provide education and training opportunities to a wide variety of aspiring healthcare professionals, including veterinarians. An essential component of the healthcare safety net, the Title VII and Title VIII programs are the only Federal programs designed to train healthcare providers in interdisciplinary settings to meet the needs of the country's special and underserved populations, as well as to increase minority representation in the healthcare workforce.

While we are keenly aware that the Subcommittee continues to face difficult decisions as it seeks to improve the Nation's fiscal health, a continued Congressional commitment to programs supporting healthcare workforce development is essential to the physical health and prosperity of the American people.

The two areas within HRSA of greatest importance to AAVMC members are the Public Health Workforce Development programs and Student Financial Assistance.

The Public Health Workforce Development programs are designed to increase the number of individuals trained in public health, to identify the causes of health problems, and to respond to such issues as managed care, new disease strains, food supply, and bioterrorism. The Public Health Traineeships and Public Health Training Centers seek to alleviate the critical shortage of public health professionals by providing up-to-date training for current and future public health workers, particularly in underserved areas. The Title VII reauthorization reorganized this cluster to include a focus on loan repayment as an incentive for public health professionals to practice in disciplines and settings experiencing shortages. The Public Health Workforce Loan Repayment Program provides loan repayment for public health professionals accepting employment with Federal, State, local, and tribal public health agencies.

AAVMC is also working to amend these authorizations so that veterinarians engaged in public health are explicitly included and prioritized for funding as their counterparts in human medicine and dentistry are. On March 8, 2011 the United States House of Representatives passed H.R. 525, the Veterinary Public Health Amendments Act. AAVMC is eager to see this legislation pass the Senate and become law so that the urgent workforce needs of veterinarians engaged in public health are fully recognized and supported, as the needs of their counterparts in human medicine are.

The loan programs under Student Financial Assistance support financially needy and disadvantaged medical and nursing school students in covering the costs of their education. The Health Professional Student Loan (HPSL) program provides loans covering the cost of attendance for financially needy health professions students based on institutional determination. The HPSL program is funded out of each institution's revolving fund and does not receive Federal appropriations. The Loans for Disadvantaged Students program provides grants to health professions institutions to make loans to health professions students from disadvantaged backgrounds.

AAVMC would also like to express concern over the pending reorganization and possible elimination of NCRR programs over the coming fiscal year. We recognize the importance of the NIH's initiative to create the National Center for Advancing Translational Sciences (NCATS) and welcome the potential benefits to our Nation's health of an invigorated focus on translational medicine and therapeutics. AAVMC's faculty members are proud of their significant contributions toward improving human health through transdisciplinary involvement and collaboration in translational research and comparative medicine. The support offered by NCRR programs and resources to our institutions and faculty have made possible their important contributions to our Nation's health.

To successfully fulfill its mission of accelerating the development and delivery of new, more effective therapeutics, NCATS will rely on a diverse team of appropriately trained laboratory scientists and clinical researchers capitalizing on the development of tools and technologies and making discoveries at molecular and cellular levels that can be tested and proven in animal-based studies. Although a logical and rational argument can be made for including NCRR's Clinical and Translational Science Award (CTSA) program, which is designed to develop teams of investigators from various fields of research who can transform scientific discoveries made in the laboratory into treatments and strategies for patients in the clinic, into the new NCATS, the same cannot be said for excluding and dismembering other components of NCRR, such as animal resources, training programs, and high-end instrumentation and technologies which are so critical to NCATS mission.

Further, as indicated in the NCRR Task Force Straw Model, proposing to subdivide these other NCRR components disrupts the extant scientific synergies that have been demonstrated meritorious to date, and forfeits the strategic relationships that have been built between programs over the last 20 years. For example, splitting the animal resources into different administrative structures erects a bureaucratic obstacle that needlessly hinders the flow of basic scientific discoveries made in induced genetic mutations in mice to clinically applicable mechanisms-of-action studied and tested in non-human primates.

Although it is expected that following this restructuring NCRR will no longer exist as a center, a rational consideration would be to maintain a large component of NCRR programs together after reassignment of the CTSA program within the

new NCATS. Those charged with making these decisions should be mindful that NCCR's unique, cross-cutting programs are and have been successful through careful planning, thoughtful leadership, and effective management by its administrative and scientific staff, program officers, and officials who understand these programs and are most qualified to ensure continued success of their respective programs and initiatives.

We urge members of this committee to examine the issues raised above and seek answers from the Administration as you conduct the constitutionally mandated responsibility of overseeing Federal agencies and their actions, such as the proposed reorganization within NIH.

Thank you for the opportunity to provide comments on the fiscal year 2012 budget for the Department of Health and Human Services. AAVMC is please to serve as a resource to Congress as you debate these important issues. Please feel free to contact me directly at 202-371-9195 x. 117 or by writing to bsmith@aaavmc.org.

PREPARED STATEMENT OF THE ASSOCIATION OF INDEPENDENT RESEARCH INSTITUTES

The Association of Independent Research Institutes (AIRI) respectfully submits this written testimony for the record to the Senate Appropriations Subcommittee on Labor, Health and Human Services, Education and Related Agencies. AIRI appreciates the commitment that the members of this Subcommittee have made to biomedical research through your strong support for the National Institutes of Health (NIH), and recommends that you maintain this support for NIH in fiscal year 2012 by providing \$31.987 billion for NIH in fiscal year 2012, which represents a 3.4 percent increase above the fiscal year 2011 level.

AIRI is a national organization of more than 80 independent, non-profit research institutes that perform basic and clinical research in the biological and behavioral sciences. AIRI institutes vary in size, with budgets ranging from a few million to hundreds of millions of dollars. In addition, each AIRI member institution is governed by its own independent board of directors, which allows our members to focus on discovery-based research while remaining structurally nimble and capable of adjusting their research programs to emerging areas of inquiry. Researchers at independent research institutes consistently exceed the success rates of the overall NIH grantee pool, and receive about 10 percent of NIH's peer-reviewed, competitively awarded extramural grants.

In recent years, Congress has taken important steps to jump start the Nation's economy through investments in science. Simultaneously, the NIH community is advancing and accelerating the biomedical research agenda in this country by focusing on scientific opportunities to address public health challenges. However, flat NIH budgets since 2003 have affected the agency's ability to pursue new, cutting-edge opportunities. This funding uncertainty is disruptive to training, careers, long-range projects, and ultimately, to research progress. The research engine needs a predictable, sustained investment in science to maximize the Nation's return.

Not only is NIH research essential to advancing health, it also plays a key economic role in communities nationwide. More than 83 percent of NIH funding is spent in communities across the Nation, creating jobs at more than 3,000 independent research institutions, universities, teaching hospitals, and other institutions in every State. NIH research also supports long-term competitiveness for American workers. NIH funding forms one of the key foundations for sustained U.S. global competitiveness in industries like biotechnology, medical device and pharmaceutical development, and more.

Highlighted below are examples of how independent research institutes uniquely contribute to the NIH mission and activities.

Translating Research into Treatments and Therapeutics.—To further its primary goal of improving health, NIH is engaged in a significant reorganization process focused on advancing translational science. AIRI looks forward to collaborating with NIH in this area as independent research institutes are particularly adept at translating basic discoveries into therapeutics, often partnering with industry. As a network of efficient, nimble independent research institutes that have been conducting translational research for years, AIRI is well-positioned to be a strong partner in bringing research from the bench to the bedside.

Currently, over 15 AIRI member institutions are affiliated and collaborate with the Clinical and Translational Science Awards (CTSA) program. Many AIRI institutes also support research on human embryonic stem cells (hESC) with the hope of discovering new and innovative disease interventions. However, uncertainty surrounding NIH funding and hESC research will hinder the agency's efforts to ad-

vance the introduction of new, life-saving cures and treatments into the marketplace.

Fostering the Next Generation Scientific Workforce.—The biomedical research community is dependent upon a knowledgeable, skilled, and diverse workforce to address current and future critical health research questions. While the primary function of AIRI member institutions is research, most are highly involved in training the next generation of biomedical researchers and ensuring that a pipeline of promising scientists are prepared to make significant and potentially transformative discoveries in a variety of areas.

AIRI supports policies that promote the United States' ability to maintain a competitive edge in biomedical science. Initiatives focusing on career development and recruitment of a diverse scientific workforce are important to innovation in biomedical research and the public health of the Nation. The cultivation and preservation of this workforce is dependent upon several factors:

- The ability to recruit scientists and students globally is essential to maintaining a strong workforce.
- Training programs both in basic and clinical biomedical research, initiatives focusing on career development, and recruiting a diverse scientific workforce are important to innovation in biomedical research for the benefit of public health.
- The continued national emphasis on promoting education in the fields of science, technology, engineering, and mathematics (STEM) is key to bolstering the pipeline.

Pursuing New Knowledge.—The NIH model for conducting biomedical research, which involves supporting scientists at universities, medical centers, and independent research institutes, provides an effective approach to making fundamental discoveries in the laboratory that can be translated into medical advances that save lives. Moreover, efforts to expand the knowledge base in medical and associated sciences bolster the Nation's economic well-being and ensure a continued high return on the public investment in research.

AIRI member institutions are private, stand-alone research centers that set their sights on the vast frontiers of medical science, specifically focused on pursuing knowledge about the biology and behavior of living systems and the application of that knowledge to improve human life and reduce the burdens of illness and disability. Additionally, AIRI member institutes have embraced technologies and research centers to collaborate on biological research for all diseases. Using advanced technology platforms or "cores," AIRI researchers use genomics, imaging, and other broad-based technologies to advance therapeutics development and drug discovery.

Providing Efficiency and Flexibility.—AIRI member institutes' small size and flexibility provide an environment that is particularly conducive to creativity and innovation. Independent research institutes possess a unique versatility and culture that encourages them to share expertise, information, and equipment across all research institutions and elsewhere. These collaborative activities help minimize bureaucracy and increase efficiency, allowing for fruitful partnerships with entities in a variety of disciplines and industries. Also, unlike institutes of higher education, independent research institutes are able to focus solely on scientific inquiry and discoveries, allowing them to respond quickly to the research needs of the country.

Supporting Local Economies.—AIRI is unique from other biomedical research organizations in that our membership consists of institutions located in regions not traditionally associated with cutting-edge research. AIRI members are located in 25 States, including many smaller or less-populated States that do not have major academic research institutions. In many of these regions, independent research institutes are major employers and economic engines, and exemplify the positive impact of investing in research and science.

AIRI thanks the Subcommittee for its important work dedicated to ensuring the health of the Nation, and we appreciate this opportunity to urge the Subcommittee to provide \$31.987 billion for NIH in the fiscal year 2012 appropriations bill. AIRI looks forward to working with Congress to support research that improves the health and quality of life for all Americans.

PREPARED STATEMENT OF THE ASSOCIATION OF MATERNAL & CHILD HEALTH PROGRAMS

Chairman Harkin and distinguished subcommittee members: On behalf of the Association of Maternal & Child Health Programs (AMCHP), I am pleased to submit testimony describing AMCHP's request for \$700 million in funding for fiscal year 2012 for the Title V Maternal and Child Health Services block grant, a 5 percent increase over fiscal year 2010. The Maternal and Child Health (MCH) Services

Block Grant supports a wide range of programs that meet State and locally determined needs. In 2008, over 40 million individuals were served by maternal and child health programs supported through the MCH Services Block Grant.

AMCHP did not develop this request lightly and our members are very cognizant of the many important and urgent discussions about reducing the Federal deficit and Government spending. However, we strongly contend that with the recent economic downturn and increased need to provide services to vulnerable populations a \$700 million request is worthy of serious consideration by the Committee.

The MCH Services Block Grant provides support and services to millions of American women, infants and children, including children with special healthcare needs. It has been proven a cost effective, value-based, and flexible funding source used to address the most pressing and unique needs of each State. States and jurisdictions use the MCH Services Block Grant to design and implement a wide range of maternal and child health programs that meet national and State needs. Although specific initiatives may vary among the 59 States and jurisdictions, all of them work to accomplish the following:

- Reduce infant mortality and incidence of disabling conditions among children;
- Increase the number of children appropriately immunized against disease;
- Increase the number of children in low-income households who receive assessments and follow-up diagnostic and treatment services;
- Provide and ensure access to comprehensive perinatal care for women; preventive and child care services; comprehensive care, including long-term care services, for children with special healthcare needs; and rehabilitation services for blind and disabled children; and
- Facilitate the development of comprehensive, family centered, community-based, culturally competent, coordinated systems of care for children with special healthcare needs.

The MCH Services Block Grant improves the health of America's women and children by:

- Supporting programs that work. The MCH Services Block Grant earned the highest program rating by the Office of Management and Budget's (OMB) Program Assessment Rating Tool (PART). OMB found that MCH Services Block Grant funded programs helped to decrease the infant mortality rate, prevent disabling conditions, increase the number of children immunized, increase access to care for uninsured children, and improve the overall health of mothers and children. Reduced MCH Services Block Grant funding threatens the ability of these programs to carry on this work. Our results are available to the public through a national website known as the Title V Information System. Such a transparent system is remarkably rare for a Federal program and we are proud of the progress we have made in demonstrating results.
- Addressing the growing health needs of women, children and families. As States face economic hardships and face limits on their Medicaid and CHIP programs, more women and children seek care and preventive services through MCH Services Block Grant funded programs. Resources are needed to reduce infant mortality, provide a range of preventive health and early intervention services to those in need, improve oral healthcare, reach more children and youth with special healthcare needs, and reduce racial disparities in healthcare.
- Supporting and integrating other federally funded programs such as Community Health Centers, Healthy Start, WIC, CHIP and Medicaid. The MCH Services Block Grant helps identify areas of need in a State and works with all State and Federal programs to complement healthcare services and promote disease prevention for women, children, and families.

To help illustrate the importance of MCH Services Block Grant funding I would like to share Michelle's story. Michelle is a young girl from Iowa who was helped by Iowa's MCH Services Block Grant supported programs.

Katrina is the mother of Michelle, an energetic, 10 year old girl from Spencer, Iowa who loves listening to music, riding and playing with horses. While enrolling her daughter into school, Katrina got a "mother's feeling" that something just wasn't quite right with her daughter and despite the family pediatrician telling her that there was nothing wrong, she reached out to the Child Health Specialty Clinic (CHSC) in Sioux City for help. It was at that Title V funded clinic that it was discovered by a professional geneticist that her child was suffering from Phelan-McDermid Syndrome (PMS). PMS is caused by damage to, or deletion of, specific genes and impacts normal childhood development. Frequently, individuals with PMS have intellectual disabilities along with little or no expressive language and often there can be a large variety of moderate and even some severe physical disabilities.

Because of the proper diagnosis from the geneticist at the specialty clinic, Katrina is able to get her daughter proper physical rehabilitation treatments twice a week from her local hospital back home in Spencer. A diagnosis of this kind could not have been found without the aid of CHSC staff and the clinic in Sioux City, which along with all Iowan CHSC clinics, are funded by the Title V Maternal & Child Health Block Grant. Title V is so valuable because CHSC clinics provide direct clinical services to children when services are not readily available in the community. CHSC clinics also provide care coordination, family support and infrastructure building, all in an effort to continue to improve healthcare for children and families across the entire state.

Thanks to Child Health Specialty Clinics, Iowan families are able to receive testing and diagnosis that they can find nowhere else. Not only are the people at these clinics determined to help children medically, they also make a point to get to know the children on a personal level. Katrina describes the people at the clinic by stating: "They know each and every child when they arrive, and they truly love the kids they see." If you were to ask Katrina how she felt about Iowa's Title V funded specialty clinics she wouldn't shy away from telling you that, "They help so much. The people there really do care."

The MCH Services Block Grant supports a similar network in every State and none of this could happen without the MCH Services Block Grant. We hope that all our Nation's citizens are as proud as Katrina because of the work of MCH Services Block Grant supported programs and professionals.

America has made huge strides in advancing the health of women and children but our country faces huge challenges in improving maternal and child health outcomes and addressing the needs of vulnerable children. On the sentinel measures of how well our society is doing to protect women and children we compare badly to other industrialized countries. Today, the United States ranks 30th in infant mortality rates and 41st in maternal mortality. Sadly, every 18 minutes a baby in America dies before his or her first birthday and each day in America we lose 12 babies due to a Sudden Unexpected Infant Death. There are places in this country where the African-American infant mortality rate is double, and in some places even triple, the rate for whites. Preventable injuries remain the leading cause of death for all children. Nationwide we still fail to adequately screen all young children for developmental concerns, and childhood obesity has reached epidemic proportions threatening to reverse a century of progress in extending life expectancy to our Nation's very future.

Without adequate funding MCH Services Block Grant programs will be overwhelmed by the mismatch between State needs and available resources. AMCHP members ask for your leadership in making the important decision to fund the MCH Services Block Grant at \$700 million for fiscal year 2012. State maternal and child health programs have a long track record of demonstrating our positive impact on MCH outcomes and are fully accountable for the funds that we receive. Maintaining vital funding for the MCH Services Block Grant is an effective and efficient way to support our Nation's women, children, and families.

In closing Mr. Chairman and distinguished members, I ask you to imagine with me an America in which every child has the opportunity to live until his or her first birthday; a Nation where our Federal and State partnership has effectively moved the needle on our most pressing maternal and child health issues such as infant mortality. Imagine all American parents being as proud as Katrina. Imagine a day when we are celebrating significant reductions or even the total elimination of health disparities by creatively solving our most urgent maternal and child health challenges.

The MCH Services Block Grant aims to do just that using resources effectively to improve the health of all of America's women and children. Supporting the MCH Services Block Grant is a cost-effective investment in our Nation's future. We appreciate you support and leadership in funding it at \$700 million for Federal fiscal year 2012.

Thank you.

PREPARED STATEMENT OF THE ASSOCIATION OF MINORITY HEALTH PROFESSIONS
SCHOOLS

Mr. Chairman and members of the subcommittee, thank you for the opportunity to present my views before you today. I am Dr. Wayne J. Riley, Chairman of the Board of Directors of the Association of Minority Health Professions Schools (AMHPS) and the President and Chief Executive Officer of Meharry Medical College. AMHPS, established in 1976, is a consortium of our Nation's 12 historically

black medical, dental, pharmacy, and veterinary schools. The members are two dental schools at Howard University and Meharry Medical College; four schools of medicine at The Charles Drew University, Howard University, Meharry Medical College, and Morehouse School of Medicine; five schools of pharmacy at Florida A&M University, Hampton University, Howard University, Texas Southern University, and Xavier University; and one school of veterinary medicine at Tuskegee University. In all of these roles, I have seen firsthand the importance of minority health professions institutions and the Title VII Health Professions Training programs.

Mr. Chairman, I want to welcome you to this new role of leading the L-HHS Subcommittee. I speak for our institutions, when I say that the minority health professions institutions and the Title VII Health Professions Training programs address a critical national need. Persistent and severe staffing shortages exist in a number of the health professions, and chronic shortages exist for all of the health professions in our Nation's most medically underserved communities. Furthermore, even after the landmark passage of health reform, it is important to note that our Nation's health professions workforce does not accurately reflect the racial composition of our population. For example while blacks represent approximately 15 percent of the U.S. population, only 2–3 percent of the Nation's health professions workforce is black. Mr. Chairman, I would like to share with you how your committee can help AMHPS continue our efforts to help provide quality health professionals and close our Nation's health disparity gap.

There is a well established link between health disparities and a lack of access to competent healthcare in medically underserved areas. As a result, it is imperative that the Federal Government continue its commitment to minority health profession institutions and minority health professional training programs to continue to produce healthcare professionals committed to addressing this unmet need—even in austere financial times.

An October 2006 study by the Health Resources and Services Administration (HRSA), entitled "The Rationale for Diversity in the Health Professions: A Review of the Evidence" found that minority health professionals serve minority and other medically underserved populations at higher rates than non-minority professionals. The report also showed that; minority populations tend to receive better care from practitioners who represent their own race or ethnicity, and non-English speaking patients experience better care, greater comprehension, and greater likelihood of keeping follow-up appointments when they see a practitioner who speaks their language. Studies have also demonstrated that when minorities are trained in minority health profession institutions, they are significantly more likely to: (1) serve in rural and urban medically underserved areas, (2) provide care for minorities and (3) treat low-income patients.

As you are aware, Title VII Health Professions Training programs are focused on improving the quality, geographic distribution and diversity of the healthcare workforce in order to continue eliminating disparities in our Nation's healthcare system. These programs provide training for students to practice in underserved areas, cultivate interactions with faculty role models who serve in underserved areas, and provide placement and recruitment services to encourage students to work in these areas. Health professionals who spend part of their training providing care for the underserved are up to 10 times more likely to practice in underserved areas after graduation or program completion.

In fiscal year 2012, funding for the Title VII Health Professions Training programs must at the very least be maintained, especially the funding for the Minority Centers of Excellence (COEs) and Health Careers Opportunity Program (HCOPs). In addition, the funding for the National Institutes of Health (NIH)'s National Institute on Minority Health and Health Disparities (NIMHD), as well as the Department of Health and Human Services (HHS)'s Office of Minority Health (OMH), should be preserved.

Minority Centers of Excellence.—COEs focus on improving student recruitment and performance, improving curricula in cultural competence, facilitating research on minority health issues and training students to provide health services to minority individuals. COEs were first established in recognition of the contribution made by four historically black health professions institutions to the training of minorities in the health professions. Congress later went on to authorize the establishment of "Hispanic", "Native American" and "Other" Historically black COEs. For fiscal year 2012, I recommend a funding level of \$24.602 million for COEs.

Health Careers Opportunity Program (HCOP).—HCOPs provide grants for minority and non-minority health profession institutions to support pipeline, preparatory and recruiting activities that encourage minority and economically disadvantaged students to pursue careers in the health professions. Many HCOPs partner with colleges, high schools, and even elementary schools in order to identify and nurture

promising students who demonstrate that they have the talent and potential to become a health professional. For fiscal year 2012, I recommend a funding level of \$22.133 million for HCOPs.

National Institutes of Health

Research Centers at Minority Institutions.—The Research Centers at Minority Institutions program (RCMI), currently administered by the National Center for Research Resources, has a long and distinguished record of helping our institutions develop the research infrastructure necessary to be leaders in the area of health disparities research. Although NIH has received unprecedented budget increases in recent years, funding for the RCMI program has not increased by the same rate. Therefore, the funding for this important program grow at the same rate as NIH overall in fiscal year 2012.

National Institute on Minority Health and Health Disparities.—The National Institute on Minority Health and Health Disparities (NIMHD) is charged with addressing the longstanding health status gap between minority and nonminority populations. The NIMHD helps health professions institutions to narrow the health status gap by improving research capabilities through the continued development of faculty, labs, and other learning resources. The NIMHD also supports biomedical research focused on eliminating health disparities and develops a comprehensive plan for research on minority health at the NIH. Furthermore, the NIMHD provides financial support to health professions institutions that have a history and mission of serving minority and medically underserved communities through the Centers of Excellence program. For fiscal year 2012, I recommend funded increases proportional with the funding of the over NIH.

Department of Health and Human Services

Office of Minority Health.—Specific programs at OMH include: assisting medically underserved communities with the greatest need in solving health disparities and attracting and retaining health professionals; assisting minority institutions in acquiring real property to expand their campuses and increase their capacity to train minorities for medical careers; supporting conferences for high school and undergraduate students to interest them in health careers, and supporting cooperative agreements with minority institutions for the purpose of strengthening their capacity to train more minorities in the health professions.

The OMH has the potential to play a critical role in addressing health disparities. For fiscal year 2012, I recommend a funding level of \$65 million for the OMH.

Department of Education

Strengthening Historically Black Graduate Institutions.—The Department of Education's Strengthening Historically Black Graduate Institutions (HBGI) program (Title III, Part B, Section 326) is extremely important to AMHPS. The funding from this program is used to enhance educational capabilities, establish and strengthen program development offices, initiate endowment campaigns, and support numerous other institutional development activities. In fiscal year 2012, an appropriation of \$65 million is suggested to continue the vital support that this program provides to historically black graduate institutions.

Mr. Chairman, please allow me to express my appreciation to you and the members of this subcommittee. With your continued help and support, AMHPS' member institutions and the Title VII Health Professions Training programs and the historically black health professions schools can help this country to overcome health disparities. Congress must be careful not to eliminate, paralyze or stifle the institutions and programs that have been proven to work. The Association seeks to close the ever widening health disparity gap. If this subcommittee will give us the tools, we will continue to work towards the goal of eliminating that disparity everyday.

Thank you, Mr. Chairman, and I welcome every opportunity to answer questions for your records.

PREPARED STATEMENT OF THE ASSOCIATION OF PUBLIC TELEVISION STATIONS

On behalf of America's 361 public television stations, we appreciate the opportunity to submit testimony for the record on the importance of Federal funding for local public television stations.

Corporation for Public Broadcasting—Fiscal Year 2014 Request: \$495 million, 2-year advance funded

More than 40 years after the inception of public television, local stations continue to serve as the treasured cultural institutions envisioned by their founders, reaching America's local communities with unsurpassed programming and services.

Public broadcasting serves the public good—in education, public affairs, public safety, cultural affairs and many other areas—and richly deserves public support. The overwhelming majority of Americans agree. In a recent bi-partisan poll conducted by Hart Research Associates/American Viewpoint, nearly 70 percent of American voters, including majorities of self-identifying Democrats, Independents, and Republicans, support continued Federal funding for public broadcasting. In addition, the same poll shows that Americans consider PBS to be the second most appropriate expenditure of public funds, behind only national defense. Federal support for CPB and local public television stations has resulted in a nationwide system of locally owned and controlled, trusted, community-driven and community responsive media entities.

Furthermore, the power of digital technology has enabled stations to greatly expand their delivery platforms to reach Americans where they are increasingly consuming media—online and on-demand—in addition to on-air. At the same time that stations are expanding their services and the impact they have in their communities, stations are also facing unprecedented funding challenges—presenting them with the greatest financial hurdles in their 40 year history. Every revenue source upon which our operations depend is under tremendous pressure. State funding support is in a wholesale free-fall. Despite serving as a long-time example of the incredible work that can be accomplished by a public-private partnership, this model is in peril as the current economic climate has put immense pressure on private funding sources. Continued Federal support for public broadcasting is more important now than ever before.

More than 70 percent of funding appropriated to CPB reaches local stations in the form of Community Service Grants (CSGs). On average, Federal spending makes up approximately 15 percent of local television station's budgets. However, for many smaller and rural stations, Federal funding represents more than 30–50 percent (and in a handful of instances, an even larger percentage) of their total budget. For all stations, this Federal funding is the “lifeblood” of public broadcasting, providing critical seed money to local stations which leverage each \$1 of the Federal investment to raise over \$6 from state legislatures, private foundations and their viewers.

Funding through CPB is absolutely essential to public television stations. Stations rely on the Federal investment to develop local programming, operate their facilities, pay their employees and provide community resources on-air, on-line and on-the-ground. This funding is particularly important to rural stations who struggle to raise local funds from individual donors due to the smaller and often economically strained population base. At the same time it is often more costly to serve rural areas due to the topography and distances between communities.

A 2007 GAO report concluded that Federal funding, such as CSGs, is an irreplaceable source of revenue, and that “substantial growth of nonFederal funding appears unlikely.” It also found that “cuts in Federal funding could lead to a reduction in staff, local programming or services.”

At an annual cost of about \$1.39 per year for each American, public broadcasting is a smart investment. This successful public-private partnership creates important economic activity while providing an essential educational and cultural service. Public broadcasting directly supports over 21,000 jobs, and of the vast majority of them are in local public television and radio stations in hundreds of communities across America.

In addition, the advent of digital technology has created enormous potential for stations, allowing them to bring content to Americans in new, innovative ways while retaining our public service mission. Public television stations are now utilizing a wide array of digital tools to expand their current roles as educators, local conveners and vital sources of trusted information at a time when their communities need them most.

For example, in an effort to confront the dropout crisis in America's high schools, CPB has just announced a significant investment and partnership with local stations and their communities to address this daunting problem that could have disastrous effects on America's future if it is not soon addressed. Together with schools and organizations that are already addressing the dropout crisis, the stations will provide their resources and services to raise awareness, coordinate action with community partners, and work directly with students, parents, teachers, mentors, volunteers and leaders to lower the drop-out rate in their respective communities.

In order for our stations to continue playing this vital role in their communities, APTS and PBS respectfully request \$495 million for CPB, two-year advance funded for fiscal year 2014.

Advance funding is essential to the mission of public broadcasting. This longstanding practice, which was enacted by President Ford in 1976, allows stations the ability to maximize fundraising efforts to leverage the promise of Federal dollars for local impact—ensuring the continuation of this strong public-private partnership. The 2-year advance funding mechanism also gives stations critical lead time needed to plan and produce high-quality programs. Additionally, the 2-year advance funding mechanism insulates programming decisions from political influence, as President Ford and the Congress intended in their initial proposal for advance funding.

Ready To Learn—Fiscal Year 2012 Request: \$27.3 million (Department of Education)

The Ready To Learn Television program's success in improving children's literacy and preparing them for school is proven and unquestioned.

Ready To Learn combines the power of public media's on-air and online educational content with on-the-ground local station community engagement to build the reading skills of children between the ages of two and eight, especially those from low-income families or those most lacking reading skills.

Over the last 5 years, 60 independent studies have proven the effectiveness of the Ready To Learn approach. For example, in one study pre-schoolers who were exposed to a curriculum composed of programming and interactive games from top Ready To Learn programs, including SUPER WHY!, Between the Lions and Sesame Street, outscored children who received a comparison (science) curriculum in all five measures of early literacy.

In addition to being research-based and teacher tested, the Ready To Learn Television program also provides excellent value for our Federal dollars. In the last five-year grant round, public broadcasting leveraged an additional \$50 million in funding to augment the \$73 million investment by the Department of Education for content production. Without the investment of the Federal Government, this supplemental investment would likely end.

The President's budget proposes consolidating public broadcasting's signature early education initiative, the Ready To Learn Television program, into a larger grant program. APTS and PBS are concerned that the consolidation of this program could lead to, at worst, the elimination of this critical program that has been the driving force behind the creation of public television's unparalleled children's educational programming. At best, the proposed budget would remove the mechanisms that have provided for the tremendously efficient and effective nature in which the Ready To Learn Television program has successfully operated.

Consolidation or elimination of the Ready To Learn Television program would severely affect the ability of local stations to respond to their communities' educational needs, removing the needed resources provided by this program for children, parents and teachers.

Ready To Learn is public television. This program is a shining example of a public-private partnership as Federal funds are leveraged to create the most popular and impactful children's educational content that is supplemented by on-line and on-the-ground resources. Without the Ready To Learn Television program, millions of families would lose access to this incredible high-quality education content, especially low-income and underserved households for whom this program is targeted.

We urge the Committee to maintain the Ready To Learn Television program as a stable line-item in the fiscal year 2012 budget and resist the calls for consolidation. APTS and PBS respectfully request level funding of \$27.3 million for the Ready To Learn Television program in fiscal year 2012.

CPB Digital Funding—Fiscal Year 2012 Request: \$36 million

Public television stations have been at the forefront of the digital transition, embracing the technology early and recognizing its benefits to their viewers. Fortunately, Congress wisely recognized that the federally mandated transition to digital broadcast would place a hardship on public television's limited resources. Since 2001, Congress has provided public television stations with funds to ensure that they have the ability to continue to meet their public service mission and deliver the highest quality educational, cultural and public affairs programming post-transition.

Although the federally mandated portion of the transition is complete, what remains to be finished is the ability of stations to fully replicate their analog services in digital. As stations have completed the transition of their main transmitters, they will continue to convert their master controls, digital storage equipment and other studio equipment—necessary to produce and distribute local educational program-

ming. The CPB Digital program is also critical to providing funds that can be invested in interactive public media that maximizes investments in digital infrastructure—including such content investments as the American Archive.

Public television has used this new public digital spectrum to maximize programming choices by offering an array of new channel options, including the national offerings of Vme (the first 24-hour, Spanish-language, educational channel), World, and Create.

More importantly, stations have also used these multicast capabilities to expand their local offerings with digital channels dedicated to community or State-focused programming. Some stations have even utilized this technology to provide gavel-to-gavel coverage of their State legislatures. In addition, digital broadcasting has enabled stations to double the amount of noncommercial, children's educational programming offered to the American public.

APTS and PBS respectfully request \$36 million in CPB Digital funding for fiscal year 2012 to enable stations to fully leverage this groundbreaking technology.

PREPARED STATEMENT OF THE ASSOCIATION OF REHABILITATION NURSES

Introduction

On behalf of the Association of Rehabilitation Nurses (ARN), I appreciate having the opportunity to submit written testimony to the Senate L-HHS Appropriations Subcommittee regarding funding for nursing and rehabilitation related programs in fiscal year 2012. ARN represents more than 5,700 Registered Nurses (RNs) who work to enhance the quality of life for those affected by physical disability and/or chronic illness. ARN understands that Congress has many concerns and limited resources, but believes that chronic illnesses and physical disabilities are heavy burdens on our society that must be addressed.

Rehabilitation Nurses and Rehabilitation Nursing

Rehabilitation nurses help individuals affected by chronic illness and/or physical disability adapt to their condition, achieve their greatest potential, and work toward productive, independent lives. They take a holistic approach to meeting patients' nursing and medical, vocational, educational, environmental, and spiritual needs. Rehabilitation nurses begin to work with individuals and their families soon after the onset of a disabling injury or chronic illness. They continue to provide support and care, including patient and family education, which empowers these individuals when they return home, or to work, or school. The rehabilitation nurse often teaches patients and their caregivers how to access systems and resources.

Rehabilitation nursing is a philosophy of care, not a work setting or a phase of treatment. These nurses base their practice on rehabilitative and restorative principles by: (1) managing complex medical issues; (2) collaborating with other specialists; (3) providing ongoing patient/caregiver education; (4) setting goals for maximum independence; and (5) establishing plans of care to maintain optimal wellness. Rehabilitation nurses practice in all settings, including freestanding rehabilitation facilities, hospitals, long-term subacute care facilities/skilled nursing facilities, long-term acute care facilities, comprehensive outpatient rehabilitation facilities, home health, and private practices, just to name a few.

With the Affordable Care Act's focus on creating a system that will increase access to quality care, emphasize prevention, and decrease cost, it is critical that a substantial investment be made in the nursing workforce programs and in the scientific research that provides the basis for nursing practice. To ensure that patients receive the best quality care possible, ARN supports Federal programs and research institutions that address the national nursing shortage and conduct research focused on nursing and medical rehabilitation, e.g., traumatic brain injury. Therefore, ARN respectfully requests that the Subcommittee provide increased funding for the following programs:

Nursing Workforce and Development Programs at the Health Resources and Services Administration (HRSA)

ARN supports efforts to resolve the national nursing shortage, including appropriate funding to address the shortage of qualified nursing faculty. Rehabilitation nursing requires a high-level of education and technical expertise, and ARN is committed to assuring and protecting access to professional nursing care delivered by highly-educated, well-trained, and experienced Registered Nurses (RNs) for individuals affected by chronic illness and/or physical disability.

According to the Health Resources and Services Administration (HRSA), in 2010, our healthcare workforce experienced a shortage of more than 400,000 nurses.¹ The demand for nurses will continue to grow as the baby-boomer population ages, nurses retire, and the need for healthcare intensifies. Implementation of the new health reform law will also increase the need for a well-trained and highly skilled nursing workforce. The Institute of Medicine has released recommendations on how to help the nursing workforce to meet these new demands, but we are destined to fall short of these lofty goals if there are not enough nurses to facilitate change.

According to the U.S. Bureau of Labor Statistics, nursing is the Nation's top profession in terms of projected job growth, with more than 581,500 new nursing positions being created through 2018.² These positions are in addition to the existing jobs that healthcare employers have not been able to fill. Educating new nurses to fill these gaping vacancies is a great way to put Americans back to work and simultaneously enhance an ailing healthcare system.

ARN strongly supports the national nursing community's request of \$313.075 million in fiscal year 2012 funding for Federal Nursing Workforce Development programs at HRSA.

National Institute on Disability and Rehabilitation Research (NIDRR)

The National Institute on Disability and Rehabilitation Research (NIDRR) provides leadership and support for a comprehensive program of research related to the rehabilitation of individuals with disabilities. As one of the components of the Office of Special Education and Rehabilitative Services at the U.S. Department of Education, NIDRR operates along with the Rehabilitation Services Administration and the Office of Special Education Programs.

The mission of NIDRR is to generate new knowledge and promote its effective use to improve the abilities of people with disabilities to perform activities of their choice in the community, and also to expand society's capacity to provide full opportunities and accommodations for its citizens with disabilities. NIDRR conducts comprehensive and coordinated programs of research and related activities to maximize the full inclusion, social integration, employment and independent living of individuals of all ages with disabilities. NIDRR's focus includes research in areas such as: employment, health and function, technology for access and function, independent living and community integration, and other associated disability research areas.

ARN strongly supports the work of NIDRR and encourages Congress to provide the maximum possible fiscal year 2012 funding level.

National Institute of Nursing Research (NINR)

ARN understands that research is essential for the advancement of nursing science, and believes new concepts must be developed and tested to sustain the continued growth and maturation of the rehabilitation nursing specialty. The National Institute of Nursing Research (NINR) works to create cost-effective and high-quality healthcare by testing new nursing science concepts and investigating how to best integrate them into daily practice. Through grants, research training, and interdisciplinary collaborations, NINR addresses care management of patients during illness and recovery, reduction of risks for disease and disability, promotion of healthy lifestyles, enhancement of quality of life for those with chronic illness, and care for individuals at the end of life. NINR's broad mandate includes seeking to prevent and delay disease and to ease the symptoms associated with both chronic and acute illnesses. NINR's recent areas of research focus include the following: End of life and palliative care in rural areas; research in multi-cultural societies; bio-behavioral methods to improve outcomes research; and increasing health promotion through comprehensive studies.

ARN respectfully requests \$163 million in fiscal year 2012 funding for NINR to continue its efforts to address issues related to chronic and acute illnesses.

Traumatic Brain Injury (TBI)

According to the Brain Injury Association of America, 1.7 million people sustain a traumatic brain injury (TBI) each year.³ This figure does not include the 150,000 cases of TBI suffered by soldiers returning from wars in Afghanistan and conflicts around the world.

The annual national cost of providing treatment and services for these patients is estimated to be nearly \$60 million in direct care and lost workplace productivity. Continued fiscal support of the Traumatic Brain Injury Act will provide critical

¹ <http://bhpr.hrsa.gov/healthworkforce/reports/nursing/rnbehindprojections/4.htm>.

² <http://www.bls.gov/oco/ocos083.htm#outlook>.

³ <http://www.biausa.org/living-with-brain-injury.htm>.

funding needed to further develop research and improve the lives of individuals who suffer from traumatic brain injury.

Continued funding of the TBI Act will promote sound public health policy in brain injury prevention, research, education, treatment, and community-based services, while informing the public of needed support for individuals living with TBI and their families.

ARN strongly supports the current work being done by the Centers for Disease Control and Prevention (CDC) and HRSA on TBI programs. These programs contribute to the overall body of knowledge in rehabilitation medicine.

ARN urges Congress to support the following fiscal year 2012 funding requests for programs within the TBI Act: \$10 million for CDC's TBI registries and surveillance, prevention and national public education and awareness efforts; \$8 million for the HRSA Federal TBI State Grant Program; and \$4 million for the HRSA Federal TBI Protection and Advocacy Systems Grant Program.

Conclusion

ARN appreciates the opportunity to share our priorities for fiscal year 2012 funding levels for nursing and rehabilitation programs. ARN maintains a strong commitment to working with Members of Congress, other nursing and rehabilitation organizations, and other stakeholders to ensure that the rehabilitation nurses of today continue to practice tomorrow. By providing the fiscal year 2012 funding levels detailed above, we believe the Subcommittee will be taking the steps necessary to ensure that our Nation has a sufficient nursing workforce to care for patients requiring rehabilitation from chronic illness and/or physical disability.

PREPARED STATEMENT OF THE BRAIN INJURY ASSOCIATION OF AMERICA

Thank you for the opportunity to submit this written testimony with regard to the fiscal year 2012 Labor-HHS-Education appropriations bill. My testimony is on behalf of the Brain Injury Association of America (BIAA), our national network of State affiliates, and hundreds of local chapters and support groups from across the country.

In the civilian population alone every year, more than 1.7 million people sustain brain injuries from falls, car crashes, assaults and contact sports. Males are more likely than females to sustain brain injuries. Children, teens and seniors are at greatest risk.

Recently, we are seeing an increasing number of service members returning from the conflicts in Iraq and Afghanistan with TBI, which has been termed one of the signature injuries of the war. Many of these returning service members are undiagnosed or misdiagnosed and subsequently they and their families will look to community and local resources for information to better understand TBI and to obtain vital support services to facilitate successful reintegration into the community.

For the past 13 years Congress has provided minimal funding through the HRSA Federal TBI Program to assist States in developing services and systems to help individuals with a range of service and family support needs following their loved one's brain injury. Similarly, the grants to State Protection and Advocacy Systems to assist individuals with traumatic brain injuries in accessing services through education, legal and advocacy remedies are woefully underfunded. Rehabilitation, community support and long-term care systems are still developing in many States, while stretched to capacity in others. Additional numbers of individuals with TBI as the result of war-related injuries only adds more stress to these inadequately funded systems.

BIAA respectfully urges you to provide States with the resources they need to address both the civilian and military populations who look to them for much needed support in order to live and work in their communities.

With broader regard to all of the programs authorized through the TBI Act, BIAA specifically requests:

- \$10 million (+\$4 million) for the Centers for Disease Control and Prevention TBI Registries and Surveillance, Brain Injury Acute Care Guidelines, Prevention and National Public Education/Awareness
- \$8 million (+\$1 million) for the Health Resources and Services Administration (HRSA) Federal TBI State Grant Program
- \$4 million (+\$1 million) for the HRSA Federal TBI Protection & Advocacy (P&A) Systems Grant Program

CDC—National Injury Center.—The Centers for Disease Control and Prevention's National Injury Center is responsible for assessing the incidence and prevalence of TBI in the United States. The CDC estimates that 1.7 million TBIs occur each year

and 3.4 million Americans live with a life-long disability as a result of TBI. In addition, the TBI Act as amended in 2008 requires the CDC to coordinate with the Departments of Defense and Veterans Affairs to include the number of TBIs occurring in the military. This coordination will likely increase CDC's estimate of the number of Americans sustaining TBI and living with the consequences.

CDC also funds States for TBI registries, creates and disseminates public and professional educational materials, for families, caregivers and medical personnel, and has recently collaborated with the National Football League and National Hockey League to improve awareness of the incidence of concussion in sports. CDC plays a leading role in helping standardize evidence based guidelines for the management of TBI and \$1 million of this request would go to fund CDC's work in this area.

HRSA TBI State Grant Program.—The TBI Act authorizes the HHS, Health Resources and Service Administration (HRSA) to award grants to (1) States, American Indian Consortia and territories to improve access to service delivery and to (2) State Protection and Advocacy (P&A) Systems to expand advocacy services to include individuals with traumatic brain injury. For the past 13 years the HRSA Federal TBI State Grant Program has supported State efforts to address the needs of persons with brain injury and their families and to expand and improve services to underserved and unserved populations including children and youth; veterans and returning troops; and individuals with co-occurring conditions

In fiscal year 2009, HRSA reduced the number of State grant awards to 15, in order to increase each monetary award from \$118,000 to \$250,000. This means that many States that had participated in the program in past years have now been forced to close down their operations, leaving many unable to access brain injury care.

Increasing the program to \$8 million will provide funding necessary to sustain the grants for the 15 States currently receiving funding along with the 3 additional States added this year and to ensure funding for 4 additional States. Steady increases over 5 years for this program will provide for each State including the District of Columbia and the American Indian Consortium and territories to sustain and expand State service delivery; and to expand the use of the grant funds to pay for such services as Information & Referral (I&R), systems coordination and other necessary services and supports identified by the State.

HRSA TBI P&A Program.—Similarly, the HRSA TBI P&A Program currently provides funding to all State P&A systems for purposes of protecting the legal and human rights of individuals with TBI. State P&As provide a wide range of activities including training in self-advocacy, outreach, information and referral and legal assistance to people residing in nursing homes, to returning military seeking veterans benefits, and students who need educational services.

Effective Protection and Advocacy services for people with traumatic brain injury is needed to help reduce Government expenditures and increase productivity, independence and community integration. However, advocates must possess specialized skills, and their work is often time-intensive. A \$4 million appropriation would ensure that each P&A can move toward providing a significant PATBI program with appropriate staff time and expertise.

NIDRR TBI Model Systems of Care.—Funding for the TBI Model Systems in the Department of Education is urgently needed to ensure that the Nation's valuable TBI research capacity is not diminished, and to maintain and build upon the 16 TBI Model Systems research centers around the country.

The TBI Model Systems of Care program represents an already existing vital national network of expertise and research in the field of TBI, and weakening this program would have resounding effects on both military and civilian populations. The TBI Model Systems are the only source of non-proprietary longitudinal data on what happens to people with brain injury. They are a key source of evidence-based medicine, and serve as a "proving ground" for future researchers.

In order to make this program more comprehensive, Congress should provide \$11 million (+ \$1.5 million) in fiscal year 2011 for NIDRR's TBI Model Systems of Care program, in order to add one new Collaborative Research Project. In addition, given the national importance of this research program, the TBI Model Systems of Care should receive "line-item" status within the broader NIDRR budget.

We ask that you consider favorably these requests for the CDC, the HRSA Federal TBI Program, and the NIDRR TBI Model Systems Program to further data collection, increase public awareness, improve medical care, assist States in coordinating services, protect the rights of persons with TBI, and bolster vital research.

PREPARED STATEMENT OF THE CAEAR COALITION

On behalf of the tens of thousands of individuals living with HIV/AIDS to whom members of the Communities Advocating Emergency AIDS Relief (CAEAR) Coalition provide care, I thank Chairman Harkin and Ranking Member Shelby for affording us the opportunity to submit testimony regarding increased funding for the Ryan White HIV/AIDS Program.

The Communities Advocating Emergency AIDS Relief (CAEAR) Coalition is a national membership organization which advocates for sound Federal policy, program regulations, and sufficient appropriations to meet the care, treatment, support service and prevention/wellness needs of people living with HIV/AIDS and the organizations that serve them, focusing on ensuring access to high quality healthcare and the evolving role of the Ryan White Program.

A Wise Investment in a Program That Works

The Ryan White Program works. In its Program Assessment Rating Tool (PART), the White House Office of Management and Budget (OMB) gave the Ryan White Program its highest possible rating of “effective”—a distinction shared by only 18 percent of all programs rated. According to OMB, effective programs “set ambitious goals, achieve results, are well-managed and improve efficiency.” Even more impressively, OMB’s assessment of the Ryan White Program found it to be in the top 1 percent of all Federal programs in the area of “Program Results and Accountability.” Out of the 1,016 Federal programs rated—98 percent of all Federal programs—the Ryan White Program was one of seven that received a score of 100 percent in “Program Results and Accountability.”

The Ryan White Program serves as the indispensable safety net for thousands of low-income, uninsured or underinsured people living with HIV/AIDS.

- Part A provides much-needed funding to the 52 major metropolitan areas hardest hit by the HIV/AIDS epidemic with severe needs for additional resources to serve those living with HIV disease in their communities.
- Part B assists States and territories in improving the quality, availability, and organization of healthcare and support services for individuals and families with HIV.
- The AIDS Drug Assistance Program (ADAP) in Part B provides life-saving, urgently needed medications to people living with HIV/AIDS in all 50 States and the territories.
- Part C provides grants to 349 faith- and community-based primary care health clinics and public health providers in 49 States, Puerto Rico and the District of Columbia. These clinics play a central role in the delivery of HIV-related medical services to underserved communities, people of color, and rural areas where Part C funded clinics provide the only HIV specific medical services available in the region.
- Part F AETC supports training for healthcare providers to identify, counsel, diagnose, treat, and manage individuals with HIV infection and to help prevent high-risk behaviors that lead to infection. It has 130 program sites with coverage in all 50 States.

CAEAR Coalition’s fiscal year 2012 funding requests for Part A, Part B base and ADAP, and Part C reflect the amounts authorized by Congress in the most recent authorization of the program.

There continues to be an increasing gap between the number of people living with HIV/AIDS in the United States in need of care and the Federal resources available to serve them. Between 2001 and 2008 the number of people living with AIDS grew 35 percent and yet funding for medical care and support services in communities with the greatest burden of HIV disease grew less than 12 percent between 2001 and 2011. Similarly, funding for Part C-funded, faith and community-based primary care clinics, which provide medical care for people living with HIV/AIDS in remote, rural and geographically isolated, urban communities nationwide, grew by only 11 percent between 2001 and 2011 as the number of people they care for grew by 52 percent. The authorized amounts we request would not fully address these funding deficiencies, but would begin to reduce the still growing gaps in funding.

We thank you in advance for your consideration of our comments and our request for:

- \$751.9 million for Part A to support grants to the cities where most people with HIV/AIDS live and receive their care and treatment.
- \$495 million for Part B base to provide additional needed resources to the States to bolster the public health response statewide regardless of location.

- \$991 million in funding for the ADAP line item in Part B so uninsured and underinsured people with HIV/AIDS can access the anti-HIV and other prescribed medications they need to survive.
- \$272.2 million for Part C to support grants to faith- and community-based organizations, healthcare agencies, and clinics.
- \$50 million to fund the 11 regional centers funded under by Part F AETC to offer specialized clinical education and consultation to frontline providers.

Sufficient Funding for Ryan White Programs Saves Money and Saves Lives

Increased funding for Ryan White Programs will reap a significant health return for minimal investment. Data show that Part A and Part C programs have reduced HIV-related hospital admissions by 30 percent nationally and by up to 75 percent in some locations. The programs supported by the Ryan White HIV/AIDS Program also have been critical in reducing AIDS mortality by 70 percent. The Ryan White Program works, resulting in both economic stimulus and social savings by helping keep people, stable, healthy and productive.

Growing Needs as More Tested and Entering Care

The Centers for Disease Control and Prevention (CDC) estimates that as of 2006 there were 1,106,400 persons living with HIV/AIDS in the United States. Approximately one-half were not in care and receiving treatment. New CDC recommendations for routine HIV testing have increased the influx of newly diagnosed individuals into care, but with 56,000 newly diagnosed individuals per year, the Federal resources have not kept pace with the burgeoning need.

The fiscal year 2012 appropriation presents a crucial opportunity to provide the Ryan White Program with the levels of funding needed to address a growing epidemic in young men, as the CDC continues to increase efforts to expand HIV testing so people living with HIV know their status, control their health, and protect others.

CAEAR Coalition supports efforts to help individuals infected with HIV learn their status at the earliest possible time. However, CAEAR Coalition is concerned about the unmet demand for services created by insufficient resources at the Federal level. Researchers estimate that CDC's expanded HIV testing guidelines will bring an additional 46,000 people into care over 5 years and significantly reduce the 21 percent of people living with HIV who do not know they are infected and therefore are not in care. Bringing these individuals into care will save large sums of money in the long run, but requires an initial investment now. Research clearly shows that averting a single HIV infection saves \$221,365 in lifetime healthcare costs¹, and getting people on anti-HIV treatment early lowers levels of HIV circulating in the body and reduces potential transmissions²—saving lives and money in the long term—but we must invest now in care and treatment to reap those rewards. Caring for individuals early in their disease will increase the cost of care by \$2.7 billion over 5 years and the majority of those costs will fall to Federal discretionary programs like the Ryan White Program and will not be offset by entitlement programs.³

Community-based providers are stretched to provide high-quality care with the scarce resources available. CAEAR Coalition is concerned that many HIV expert medical staff are scheduled to retire and the persistent financial pressures may accelerate the loss of trained professionals in the field. This additional pressure on an already overburdened system will leave many of the more than 200,000 HIV-infected individuals who do not know their HIV status without access to the care they need.

State budget cuts have created a continuing and growing ADAP funding crisis as a record number of people are in need of ADAP services due to the economic downturn. As of May 2011, there are 8,100 people on ADAP waiting lists in 13 States. Additionally, ADAP waiting lists and other cost-containment measures, including limited formularies, reducing eligibility, or removing already enrolled people from the program, are clear evidence that the need for HIV-related medications continues to outstrip availability. ADAPs are forced to make difficult trade-offs between serving a greater number of people living with HIV/AIDS with fewer services or serving

¹Holtgrave DR, Briddell K, Little E, Bendixen AV, Hooper M, Kidder DP, et al. Cost and threshold analysis of housing as an HIV prevention intervention. *AIDS & Behavior*.(2007)11(Suppl 2), S162–S166.

²Montaner J, Lima VD, Barrios R, et al. Association of highly active antiretroviral therapy coverage, population viral load, and yearly new HIV diagnoses in British Columbia, Canada: a population-based study. *The Lancet* (2010) 376(9740): 532–539.

³Martin EG, Paltiel AD, Walensky, RP, Schackman BR, Expanded HIV Screening in the United States: What Will It Cost Government Discretionary and Entitlement Programs? *A Budget Impact Analysis. Value in Health* (2010) 13: 893–902.

fewer people with more services. Additional resources are needed to reduce and prevent further use of cost-containment measures to limit access to ADAPs and to allow all State ADAPs to provide a full range of HIV antiretrovirals and treatment for opportunistic infections.

The number of clients entering the 349 Part C community health centers and outpatient clinics has consistently increased over the last 5 years. Over 247,000 unduplicated persons living with HIV/AIDS receive medical care in Part C-funded community health centers and clinics each year. These faith- and community-based HIV/AIDS providers are staggering under the burden of treatment and care after years of funding cuts prior to the modest increase in recent years. The success of the CDC's routine HIV testing recommendations has generated new clients for Part C-funded health centers and clinics too, but unfortunately with no increase in funding to provide the high quality healthcare services and treatment access people with HIV/AIDS require.

Ryan White-Funded Programs are Economic Engines in their Communities

Ryan White—funded programs, including many community health centers, are small businesses providing jobs, vendor contracts and other types of economic development to low-income, urban and rural communities, frequently serving as anchors for existing and new businesses and investments. These organizations employ people in their communities, providing critical entry-level jobs, community-based training and career building.

For example, a large, urban community health center brings an estimated economic impact of \$21.6 million, employing 281 people, and a small, rural health center has an estimated economic impact of \$3.9 million, employing 52 people. Investing in AIDS care and treatment is an investment in jobs and community development in communities that need it most.

Ryan White Program Key to Meeting the Goals of the National HIV/AIDS Strategy

CAEAR Coalition is eager to work with Congress to meet the challenges posed by the HIV/AIDS epidemic. In 2012, we have the collective chance to implement the community-embraced healthcare goals and policies in the National HIV/AIDS Strategy (NHAS). The National Strategy is an opportunity to reinvigorate the Nation's response to the HIV/AIDS epidemic and stop its relentless movement into our communities. The Ryan White HIV/AIDS Program is key to reaching the NHAS goals of reducing new HIV infections, increasing access to care and improving health outcomes for people living with HIV/AIDS, and reducing HIV-related health disparities. Ryan White provides HIV/AIDS care and treatment services to a significantly higher proportion of racial/ethnic minorities and women than their representation among reported AIDS cases—suggesting the programs and resources are targeted to underserved and marginalized populations. Early care and treatment are more critical than ever because we can help those infected learn their status and get into care and treatment in order to improve their own health and the health of their communities.

The Ryan White Program's history of accomplishments for public health and people living with HIV/AIDS is a wonderful legacy for the U.S. Congress. There continues to be a vast need for additional resources to address the healthcare and treatment needs of people living with HIV across the country. In recognition of its high level of effectiveness and validation over time from credible Federal Government institutions, CAEAR urges the committee to provide the Ryan White HIV/AIDS Program with the funding levels authorized by Congress for fiscal year 2012.

PREPARED STATEMENT OF THE CENTERS FOR DISEASE CONTROL AND PREVENTION
(CDC) COALITION

The CDC Coalition is a nonpartisan coalition of more than 140 organizations committed to strengthening our Nation's prevention programs. Our mission is to ensure that health promotion and disease prevention are given top priority in Federal funding, to support a funding level for the Centers for Disease Control and Prevention (CDC) that enables it to carry out its prevention mission, and to assure an adequate translation of new research into effective State and local programs. Coalition member groups represent millions of public health workers, clinicians, researchers, educators, and citizens served by CDC programs.

The CDC Coalition believes that Congress should support CDC as an agency—not just the individual programs that it funds. In the best judgment of the CDC Coalition—given the challenges and burdens of chronic disease, a potential influenza pandemic, terrorism, disaster preparedness, new and reemerging infectious diseases and our many unmet public health needs and missed prevention opportunities—we

believe the agency will require funding of at least \$7.7 billion for CDC's "core programs" in fiscal year 2012. This request represents a 36 percent increase over fiscal year 2011 and a 31 percent increase over the President's fiscal year 2012 request. We are deeply disappointed with the more than \$740 million in cuts to CDC's budget authority included in the proposed fiscal year 2011 continuing resolution (CR). While CDC programs will receive significant new funding from the Prevention and Public Health Fund in fiscal year 2011, we are concerned that this funding would essentially supplant cuts made to CDC's budget authority. As you know the Prevention and Public Health Fund was intended to supplement and not supplant the base funding of our public health agencies and programs.

By translating research findings into effective intervention efforts, CDC has been a key source of funding for many of our State and local programs that aim to improve the health of communities. Perhaps more importantly, Federal funding through CDC provides the foundation for our State and local public health departments, supporting a trained workforce, laboratory capacity and public health education communications systems.

CDC also serves as the command center for our Nation's public health defense system against emerging and reemerging infectious diseases. With the potential onset of a worldwide influenza pandemic, in addition to the many other natural and man-made threats that exist in the modern world, the CDC has become the Nation's—and the world's—expert resource and response center, coordinating communications and action and serving as the laboratory reference center. States and communities rely on CDC for accurate information and direction in a crisis or outbreak.

The Multiple Roles of CDC

CDC serves as the lead agency for bioterrorism and other public health emergency preparedness and must receive sustained support for its preparedness programs in order for our Nation to meet future challenges. Given the challenges of terrorism and disaster preparedness, and our many unmet public health needs and missed prevention opportunities we urge you to provide adequate funding for State and local capacity grants. We ask the Subcommittee to ensure that our States and local communities are prepared in the event of an act of terrorism or other public health threat this year and in future years. Unfortunately, this is not a threat that is going away.

Addressing the Leading Causes of Death and Disability

The President's fiscal year 2012 budget proposes to consolidate a number of chronic disease programs within CDC. Members of the CDC Coalition are currently engaged in conversations with CDC and members of Congress to better understand what this consolidation will mean for the funding that is passed on to our State and local health and education agencies and the various programs our members have supported in the past. We look forward to working with Congress, the administration and CDC to ensure that any effort to consolidate programs leads to the best health outcomes for the American people. We must ensure that CDC's National Center for Chronic Disease Prevention and Health Promotion has the resources it needs to assist our States and communities in their efforts to reduce the burden of chronic disease.

Heart disease remains the Nation's No. 1 killer. In 2007, over 616,000 people in the United States died from heart disease, accounting for nearly 25 percent of all U.S. deaths. More women than men die of heart disease each year, and in 2007, females had higher rates of inpatient heart attack mortality than males. Stroke is the third leading cause of death and is a leading cause of disability. In 2007, stroke killed more than 135,000 people (61 percent of them women), accounting for about 1 of every 18 deaths.

Cancer is the second most common cause of death in the United States. There were an estimated 1,529,560 new cancer cases and 569,490 deaths from cancer in 2010. The financial cost of cancer is also significant. According to the National Institutes of Health (NIH), in 2008 the overall cost for cancer in the United States was more than \$228.1 billion: \$93.2 billion for direct medical costs, \$18.8 billion for lost worker productivity due to illness, and \$116.1 billion for lost worker productivity due to premature death.

Among the ways CDC is fighting cancer, is through funding the National Breast and Cervical Cancer Early Detection Program that helps low-income, uninsured and medically underserved women gain access to lifesaving breast and cervical cancer screenings and provides a gateway to treatment upon diagnosis. CDC also funds grants to States to develop Comprehensive Cancer Control (CCC) plans, bringing together a broad partnership of public and private stakeholders to set joint priorities

and implement specific cancer prevention and control activities customized to address each State's particular needs.

Although more than 25.8 million Americans have diabetes, nearly 7 million cases are undiagnosed. In 2010, about 1.9 million people aged 20 years or older were newly diagnosed with diabetes. Diabetes is the leading cause of kidney failure, non-traumatic lower-limb amputations, and new cases of blindness among adults in the United States. The total direct and indirect costs associated with diabetes were \$178 billion in 2007. Preventive care such as routine eye and foot examinations, self-monitoring of blood glucose, and glycemic control could reduce these numbers.

Over the last 25 years, obesity rates have doubled among adults and children, and tripled in teens. Obesity, diet and inactivity are cross-cutting risk factors that contribute significantly to heart disease, cancer, stroke and diabetes. CDC funds programs to encourage the consumption of fruits and vegetables, encourage sufficient exercise, and to develop other habits of healthy nutrition and activity.

An estimated 443,000 people die prematurely every year due to tobacco use. CDC's tobacco control efforts seek to prevent tobacco addiction in the first place, as well as help those who want to quit. We must continue to support these vital programs and reduce tobacco use in the United States.

Each day more than 3,900 young people initiate cigarette smoking. At the same time, according to CDC, only 3.8 percent of elementary schools, 7.9 percent of middle schools and 2.1 percent of high schools provide daily physical education or its equivalent for the entire school year. Almost 90 percent of young people do not eat the recommended number of servings of fruits and vegetables, while nearly 30 percent of young people are overweight or at risk of becoming overweight. And every year, almost 800,000 adolescents become pregnant and nearly 4 million teens are infected with a sexually transmitted disease. CDC plays a critical role in ensuring good public health and health promotion in our schools.

CDC provides national leadership in helping control the HIV epidemic by working with community, State, national, and international partners in surveillance, research, prevention and evaluation activities. CDC estimates that about 1.1 million Americans are living with HIV, 21 percent of who are undiagnosed. Also, the number of people living with HIV is increasing, as new drug therapies are keeping HIV-infected persons healthy longer and dramatically reducing the death rate. Prevention of HIV transmission is the best defense against the AIDS epidemic that has already killed more than 617,000 in the United States and dependant areas and is devastating populations around the globe.

The United States has the highest rates of sexually transmitted diseases (STDs) in the industrialized world. More than 19 million new infections occur each year, almost half of them among young people. CDC estimates that STDs, including HIV, cost the U.S. healthcare system as much as \$15.3 billion annually. Over the past several years, significant ground has been lost in the fight against STDs. While syphilis was on the verge of elimination in the United States at the start of the decade, rates have increased by 114 percent since 2000. An adequate investment in STD prevention could save millions in annual healthcare costs in the future.

CDC and its National Center for Health Statistics collect data on chronic disease prevalence, health disparities, emergency room use, teen pregnancy, infant mortality and causes of death. The health data collected through the Behavioral Risk Factor Surveillance System, Youth Risk Behavior Survey, Youth Tobacco Survey, National Vital Statistics System, and National Health and Nutrition Examination Survey are an essential part of the Nation's statistical and public health infrastructure. Adequate funding for these activities is essential for tracking America's health as a nation and developing targeted and appropriate public health policies and prevention interventions.

We must address the growing disparity in the health of racial and ethnic minorities. CDC is helping States address serious disparities in infant mortality, breast and cervical cancer, cardiovascular disease, diabetes, HIV/AIDS and immunizations. Our members are committed to ending the disparities and we encourage the Subcommittee to provide adequate funds for these efforts.

CDC oversees immunization programs for children, adolescents and adults, and is a global partner in the ongoing effort to eradicate polio worldwide. The value of adult immunization programs to improve length and quality of life, and to save healthcare costs, is realized through a number of CDC programs, but there is much work to be done and a need for sound funding to achieve our goals. Influenza vaccination levels remain low for adults. Levels are substantially lower for pneumococcal vaccination and significant racial and ethnic disparities in vaccination levels persist among the elderly. In addition, developing functional immunization registries in all States will be less costly in the long run than maintaining the incomplete systems currently in place.

Childhood immunizations provide one of the best returns on investment of any public health program. For every dollar spent on seven vaccines recommended in the childhood series, \$16.50 is saved in direct and indirect costs. An estimated 14 million cases of childhood disease and 33,000 deaths are prevented each year through timely immunization. Despite the incredible success of the program, it faces serious financial challenges.

Injuries are the leading causes of death for persons aged 1–44 years. Unintentional injuries and violence such as older adult falls, unintentional drug poisonings, child maltreatment and sexual violence accounts for over 35 percent of emergency department visits annually. Annually, injury and violence cost the United States approximately \$406 billion in direct and indirect medical costs including lost productivity. Unintentional injury consistently remains the leading cause of death among young Americans ages 1–34 with 37.1 percent of unintentional fatal injuries caused by motor vehicle traffic fatalities. Conversely, violence related injuries are also substantial with homicide being the second leading cause of death for persons 15–24 years, while suicide is the 11th leading cause of death across all age groups. The consequences of these injuries can be far reaching from physical, emotional, financial turmoil to long term disability. CDC's Injury Center works to prevent unintentional and violence-related injuries to minimize the consequences of injuries when they occur by researching the problem; identifying the risk and protective factors; developing and testing interventions; ensuring widespread adoption of proven strategies and gathering data to assist States and communities to develop prevention programs and practices through the use of surveillance systems like the National Violent Death Reporting System.

One in every 33 babies born each year in the United States is born with one or more birth defects. Birth defects are the leading cause of infant mortality. Children with birth defects who survive often experience lifelong physical and mental disabilities. More than 50 million people in the United States currently live with a disability, and 17 percent of children under the age of 18 have a developmental disability. The National Center on Birth Defects and Developmental Disabilities at CDC conducts programs to protect and improve the health of children and adults by preventing birth defects and developmental disabilities; promoting optimal child development and health and wellness among children and adults with disabilities.

We also encourage the Subcommittee to provide adequate funding for CDC's Center for Environmental Health to revitalize environmental public health services at the national, State and local level and sustain current programs. These services are essential to protecting and ensuring the health and well being of the American public from threats associated with West Nile virus, climate change, terrorism, E. coli, lead-based paint and other hazards.

We appreciate the Subcommittee's past support for CDC programs in a climate of competing priorities. We thank you for considering our fiscal year 2012 request for \$7.7 billion for CDC's "core programs."

PREPARED STATEMENT OF THE CHARLES R. DREW UNIVERSITY OF MEDICINE AND
SCIENCE

Mr. Chairman and members of the Subcommittee, thank you for the opportunity to present you with testimony. The Charles Drew University is distinctive in being the only dually designated Historically Black Graduate Institution and Hispanic Serving Institution in the Nation. We would like to thank you, Mr. Chairman, for the support that this subcommittee has given to our University to produce minority health professionals to eliminate health disparities as well as do groundbreaking research to save lives.

The Charles Drew University is located in the Watts-Willowbrook area of South Los Angeles. Its mission is to prepare predominantly minority doctors and other health professionals to care for underserved communities with compassion and excellence through education, clinical care, outreach, pipeline programs and advanced research that makes a rapid difference in clinical practice. The Charles Drew University has established a national reputation for translational research that addresses the health disparities and social issues that strike hardest and deepest among urban and minority populations.

Health Resources and Services Administration

Title VII Health Professions Training Programs.—The health professions training programs administered by the Health Resources and Services Administration (HRSA) are the only Federal initiatives designed to address the longstanding under representation of minorities in healthcareers. HRSA's own report, "The Rationale for

Diversity in the Health Professions: A Review of the Evidence,” found that minority health professionals disproportionately serve minority and other medically underserved populations, minority populations tend to receive better care from practitioners of their own race or ethnicity, and non-English speaking patients experience better care, greater comprehension and greater likelihood of keeping follow-up appointments when they see a practitioner who speaks their language. Studies have also demonstrated that when minorities are trained in minority health professions institutions, they are significantly more likely to: (1) serve in medically underserved areas, (2) provide care for minorities and (3) treat low-income patients.

Minority Centers of Excellence.—The purpose of the COE program is to assist schools, like Charles Drew University, that train minority health professionals, by supporting programs of excellence. The COE program focuses on improving student recruitment and performance; improving curricula and cultural competence of graduates; facilitating faculty and student research on minority health issues; and training students to provide health services to minority individuals by providing clinical teaching at community-based health facilities. For fiscal year 2012, the funding level for COE should be \$24.602 million.

Health Careers Opportunity Program.—Grants made to health professions schools and educational entities under HCOP enhance the ability of individuals from disadvantaged backgrounds to improve their competitiveness to enter and graduate from health professions schools. HCOP funds activities that are designed to develop a more competitive applicant pool through partnerships with institutions of higher education, school districts, and other community based entities. HCOP also provides for mentoring, counseling, primary care exposure activities, and information regarding careers in a primary care discipline. Sources of financial aid are provided to students as well as assistance in entering into health professions schools. For fiscal year 2012, the HCOP funding level of \$22.133 million is recommended.

National Institutes of Health

National Institute on Minority Health and Health Disparities.—The NIMHD is charged with addressing the longstanding health status gap between under-represented minority and non minority populations. The NIMHD helps health professional institutions to narrow the health status gap by improving research capabilities through the continued development of faculty, labs, telemedicine technology and other learning resources. The NIMHD also supports biomedical research focused on eliminating health disparities and developed a comprehensive plan for research on minority health at NIH. Furthermore, the NIMHD provides financial support to health professions institutions that have a history and mission of serving minority and medically underserved communities through the COE program and HCOP. For fiscal year 2012, an increase proportional to NIH’s increase is recommended for NIMHD to support these critical activities.

Research Centers At Minority Institutions.—RCMI at the National Center for Research Resources (NCRR) has a long and distinguished record of helping institutions like The Charles Drew University develop the research infrastructure necessary to be leaders in the area of translational research focused on reducing health disparities research. Although NIH has received some budget increases over the last 5 years, funding for the RCMI program has not increased by the same rate. Therefore, the funding for this important program grow at the same rate as NIH overall in fiscal year 2012.

Department of Health and Human Services

Office of Minority Health.—Specific programs at OMH include: assisting medically underserved communities, supporting conferences for high school and undergraduate students to interest them in healthcareers, and supporting cooperative agreements with minority institutions for the purpose of strengthening their capacity to train more minorities in the health professions. For fiscal year 2012, I recommend a funding level of \$65 million for OMH to support these critical activities.

Department of Education

Strengthening Historically Black Graduate Institutions.—The Department of Education’s Strengthening Historically Black Graduate Institutions program (Title III, Part B, Section 326) is extremely important to MMC and other minority serving health professions institutions. The funding from this program is used to enhance educational capabilities, establish and strengthen program development offices, initiate endowment campaigns, and support numerous other institutional development activities. In fiscal year 2012, an appropriation of \$65 million is suggested to continue the vital support that this program provides to historically black graduate institutions.

Conclusion

Despite all the knowledge that exists about racial/ethnic, socio-cultural and gender-based disparities in health outcomes, the gap continues to widen. Not only are minority and underserved communities burdened by higher disease rates, they are less likely to have access to quality care upon diagnosis. As you are aware, in many minority and underserved communities preventative care and research are inaccessible either due to distance or lack of facilities and expertise. As noted earlier, in just one underserved area, South Los Angeles, the number and distribution of beds, doctors, nurses and other health professionals are as parlous as they were at the time of the Watts Rebellion, after which the McCone Commission attributed the so-named “Los Angeles Riots” to poor services—particularly access to affordable, quality healthcare. The Charles Drew University has proven that it can produce excellent health professionals who ‘get’ the mission—years after graduation they remain committed to serving people in the most need. But, the university needs investment and committed increased support from Federal, State and local governments and is actively seeking foundation, philanthropic and corporate support.

Even though institutions like The Charles Drew University are ideally situated (by location, population, community linkages and mission) to study conditions in which health disparities have been well documented, research is limited by the paucity of appropriate research facilities. With your help, the Life Sciences Research Facility will translate insight gained through research into greater understanding of disparities and improved clinical outcomes. Additionally, programs like Title VII Health Professions Training programs will help strengthen and staff facilities like our Life Sciences Research Facility.

We look forward to working with you to lessen the huge negative impact of health disparities on our Nation’s increasingly diverse populations, the economy and the whole American community.

Mr. Chairman, thank you again for the opportunity to present testimony on behalf of The Charles Drew University. It is indeed an honor.

PREPARED STATEMENT OF THE CHILDREN’S ENVIRONMENTAL HEALTH NETWORK

On behalf of the Children’s Environmental Health Network (CEHN), a national multi-disciplinary organization whose mission is to protect the fetus and the child from environmental health hazards and promote a healthy environment, I thank you for the opportunity to submit testimony in support of fiscal year 2012 appropriations for U.S. Department of Health and Human Services (HHS) for activities that protect children from environmental hazards.

CEHN appreciates the wide range of needs that you must consider for funding. We urge you to give priority to those programs that directly protect and promote children’s environmental health. In so doing, you will improve not only our children’s health and development, but also their educational outcomes and their future.

The world in which today’s children live has changed tremendously from that of previous generations, including a phenomenal increase in the substances to which children are exposed. Every day, children are exposed to a mix of chemicals, most of them untested for their effects on developing systems. In general, children have unique vulnerabilities and susceptibilities to toxic chemicals. In some cases, an exposure which may cause little or no harm to an adult may lead to irreparable damage to a child. Exposure to neurotoxicants in utero or early childhood can result in life-long learning and developmental delays.

Investments in programs that protect and promote children’s health will be repaid by healthier children with brighter futures. Protecting our children—those born as well as those yet to be born—from environmental hazards is truly a national security issue. Cutting or weakening programs that protect children from harmful chemicals in their environment is not only very costly to our Nation (for example, the Clean Air Act Amendments of 1990 have saved \$1 trillion in healthcare costs¹), such cuts will reduce the number of exceptionally bright children in future generations. Our Nation’s future will depend upon its future leaders. As our experience with removing lead from gasoline illustrates (removing lead in gasoline has saved the United States an estimated \$200 billion each year since 1980 in the form of

¹Health and Welfare Benefits Analyses to Support the Second Section 812 Benefit-Cost Analysis of the Clean Air Act, Final Report, prepared by Industrial Economics for the U.S. EPA, February 2011.

higher IQs for that year's newborns)², when we protect children from harmful chemicals in their environment, we help to assure that they will reach their full potential. We have a responsibility to our Nation's children, and to the Nation that they will someday lead, to provide them with a healthy environment.

Additionally, American competitiveness depends on having healthy educated children who grow up to be healthy productive adults. Yet, growing numbers of our children are diagnosed with chronic and developmental illnesses and disabilities. The National Academy of Sciences estimates that toxic environmental exposures play a role in 28 percent of neurobehavioral disorders in children and this does not include other conditions such as asthma or cancers. Thus it is vital that the Federal programs and activities that protect children from environmental hazards receive adequate resources. Key programs in your jurisdiction which CEHN urges you to support include:

Centers for Disease Control and Prevention (CDC)

The CDC is the Nation's leader in public health promotion and disease prevention, and should receive top priority in Federal funding. CDC continues to be faced with unprecedented challenges and responsibilities. CEHN applauds your support for CDC in past years and urges you to support a funding level of \$7.7 billion for CDC's core programs in fiscal year 2012.

Within CDC, the National Center for Environmental Health (NCEH) is particularly important to protecting the environmental health of young children. NCEH programs, such as its efforts to continue and expand biomonitoring and its national report card on exposure information, are key national assets. CEHN is thus deeply concerned about the proposed severe cuts to CDC's environmental public health programs in the President's fiscal year 2012 budget. We join with many others in strongly opposing the proposal to consolidate CDC's Healthy Homes/Lead Poisoning Prevention and the National Asthma Control Programs and reducing funding for these programs by more than half.

The CDC's National Environmental Public Health Tracking Program helps to track environmental hazards and the diseases they may cause and to coordinate and integrate local, State and Federal health agencies' collection of critical health and environmental data. Public health officials need integrated health and environmental data so that they can protect the public's health. We urge you to reverse the CDC operating plan for fiscal year 2011, which eliminates all budget authority for this vital program. We urge you to support additional funding for the program in fiscal year 2012.

The Built Environment and Health Program (also known as the Healthy Community Design Initiative) would be abolished. Other cuts to the center's core environmental work include its radiation activities and building capacity in local health departments. We urge you to oppose these cuts.

CEHN also strongly supports CDC's Environmental Health Laboratory and its biomonitoring activities, which allow us to measure with great precision the actual levels of more than 450 chemicals and nutritional indicators in people's bodies. This information helps public health officials to determine which population groups are at high risk for exposure and adverse health effects, assess public health interventions, and monitor exposure trends over time.

National Institutes of Health (NIH)

CEHN joins others in the health field in requesting that the Committee provide \$35 billion for the National Institutes of Health (NIH) in fiscal year 2012, including \$779.4 million for the National Institute of Environmental Health Sciences (NIEHS).

NIEHS is the leading institute conducting research to understand how the environment influences the development and progression of human disease. Children are uniquely vulnerable to harmful substances in their environment, and the NIEHS plays a critical role in uncovering the connections between environmental exposures and children's health. Thus it plays a vital role in our efforts to understand how to protect children, whether it is identifying and understanding the impact of substances that are endocrine disruptors or understanding childhood exposures that may not affect health until decades later.

CEHN therefore urges you to provide \$779.4 million for NIEHS in fiscal year 2012.

²"Economic Gains Resulting from the Reduction in Children's Exposure to Lead in the United States," Grosse SD, Matte TD, Schwartz J, Jackson RJ, Environ Health Perspectives 2002, 110(6): doi:10.1289/ehp.02110563

Children's Environmental Health Research Centers of Excellence

The Children's Environmental Health Research Centers, jointly funded by the NIEHS and the EPA, play a key role in providing the scientific basis for protecting children from environmental hazards. With their modest budgets, which have been unchanged for more than 10 years, these centers generate valuable research. A unique aspect of these Centers is the requirement that each Center actively involves its local community in a collaborative partnership, leading both to community-based participatory research projects and to the translation of research findings into child-protective programs and policies. The scientific output of these centers has been outstanding. For example, findings from four Centers clearly showed that prenatal exposure to a widely used pesticide affected developmental outcomes at birth and early childhood. This was important information to EPA's decision makers in their regulation of this pesticide.

Several Centers have established longitudinal cohorts which have resulted in valuable research results. The Network is concerned that as a Center's multi-year grant ends and the Center is shuttered, these cohorts and the invaluable information they can provide are being lost. The Network urges the Committee to assure that NIEHS has the funding and the direction to support Centers in continuing these cohorts.

The work of these Centers has also shown us that, in addition to research regarding a specific pollutant or health outcome, research is desperately needed in understanding the totality of the child's environment—for example, all of the exposures the child experiences in the home, school, and child care environment—and how to evaluate those multiple factors. CEHN urges you to support these Centers, to assure they receive full funding and are extended and expanded as described above.

National Children's Study

CEHN urges the Committee to assure stable support for the National Children's Study (NCS) for all Institutes involved in this landmark, evidence-based longitudinal study examining the effects of environmental influences on the health and development of more than 100,000 children across the United States. This study may be the only means that we will have to understand the links between exposures and the health and development of children and to identify the antecedents for a healthy adulthood. 2012 will be a critical year for the NCS. It is vital that the funding is in place to launch the main study involving all of the centers. Already approximately 700 babies have been born into the study.

We urge the Committee to assure that the NCS retains on its original focus on environmental chemicals. While the NCS is housed at NIH, it must be a multi-agency study and it must be responsive to its mission and to the lead agencies, in and out of NIH.

CEHN also asks the Committee to direct NIH to ensure that protocols are in place within NCS for measuring exposures in child care and school settings; it is critically important to understand how school and child care exposures differ from home exposures very early in the study process.

Pediatric Environmental Health Specialty Units

Funded jointly by the Agency for Toxic Substances and Disease Registry (ATSDR) and the U.S. Environmental Protection Agency (EPA), the Pediatric Environmental Health Specialty Units (PEHSUs) form a valuable resource network, with a center in each of the U.S. Federal regions. PEHSU professionals provide medical consultation to healthcare professionals on a wide range of environmental health issues, from individual cases of exposure to advice regarding large-scale community issues. PEHSUs also provide information and resources to school, child care, health and medical, and community groups to help increase the public's understanding of children's environmental health, and help inform policymakers by providing data and background on local or regional environmental health issues and implications for specific populations or areas. For example, following the gulf oil spill in 2010, the PEHSUs quickly produced and released a series of factsheets and advisories in multiple languages for local patients and health professionals. We urge the Committee to fully fund ATSDR's portion of this program in fiscal year 2012.

In conclusion, investments in programs that protect and promote children's health will be repaid by healthier children with brighter futures, an outcome we can all support. That is why CEHN asks you to give priority to these programs. Thank you for the opportunity to comment. CEHN's staff and I would be happy to answer any questions you may have.

PREPARED STATEMENT OF THE COALITION FOR HEALTH FUNDING

The Coalition for Health Funding is pleased to provide the Senate Labor, Health and Human Services, Education and Related Agencies Appropriations Subcommittee with a statement for the record on fiscal year 2012 funding levels for health agencies and programs. Since 1970, the Coalition for Health Funding has advocated for sufficient and sustained discretionary funding for the public health continuum to meet the mounting and evolving health challenges confronting the American people.

Our Nation's strength is inextricably linked to our health. Evidence abounds—from the Department of Defense to the U.S. Chamber of Commerce—that healthy Americans are stronger on the battlefield, have higher academic achievement, and are more productive in school and on the job. Federal funding helps discover cures and fuel innovation, ensure the safety of our drugs, food, water, and air, prevent disease, protect and respond in times of crisis, train healthcare professionals, and provide care to our Nation's most vulnerable. Much of what public health does—and the impact of Federal investment in it—is such a part of Americans' daily living that it is often invisible and almost always taken for granted. For example, Federal health funding has:

- Improved and saved the lives of many of those suffering from illnesses through scientific innovation and discovery.
- Prevented unnecessary and costly injuries through seat belt and helmet laws, mandatory airbags, and car seats for infants and toddlers.
- Promoted safe and healthy foods through dietary guidelines and food labeling that help Americans better understand what we eat and how to eat better.
- Improved the health of mothers and reduced birth defects and infant deaths through recommendations to take folic acid during early stages of pregnancy, place babies on their backs to prevent Sudden Infant Death Syndrome, and avoid tobacco and alcohol use during pregnancy.
- Combated tobacco addiction by regulating advertisements, imposing age limits on tobacco purchases, and instituting smoking bans in public places, cutting smoking rates by nearly half and reducing the number of smoking-related deaths and illnesses and the opportunity and real costs associated with them.
- Treated and eradicated infectious diseases through vaccines, preventing epidemics and saving lives.
- Improved the environment through bans on asbestos in household products and lead in paint and gasoline.
- Protected the American people in all communities from infectious, occupational, environmental, and terrorist threats.

These are just some of the ways in which Federal funding for public health has changed our lives and those of our children for the better. Still, Federal funding is necessary to further improve, save, and protect those in America and around the world. The treatments and cures for many devastating diseases are just out of reach. Racial, socioeconomic, and geographic health disparities persist. Costly and often preventable chronic conditions such as asthma, diabetes, heart disease and obesity—particularly among young people—are on the rise and threaten military readiness, academic achievement, and societal productivity. The failure to prioritize behavioral health issues continues to have stunning, debilitating social and economic consequences. Oral health is still not widely recognized as a healthcare priority in spite of the fact that tooth decay remains a common chronic disease among all ages and is preventable.

The Coalition for Health Funding's 70 national, member organizations—representing the interests of more than 100 million patients, healthcare providers, public health professionals, and scientists—support the belief that the Federal Government is an essential partner with State and local governments and the nonprofit and private sectors in improving health. A pressing and immediate goal is to build the capacity of our public health system to address America's mounting health needs under the weight of a fragile economy, an aging population, a health workforce shortage, and persisting declines in health status.

Given current fiscal challenges, the Coalition for Health Funding appreciates the efforts of the President and Congress to maintain funding for many critical health programs in the final fiscal year 2011 spending legislation. Nevertheless, the Coalition remains concerned about prospects for future cuts to health programs. The Coalition supports fiscal responsibility, but not at the expense of America's health and well-being. Cuts to federally funded health services and scientific research will not significantly reduce the deficit, nor make a dent in the national debt; discretionary health spending represents less than 2 percent of all Federal spending. These cuts adversely affect American families, cost jobs, and ultimately compromise America's global competitiveness and economic growth.

The Coalition for Health Funding organized more than 470 national, State, and local organizations and six former Surgeons General in a letter that urged Congress to increase discretionary health funding. The following list summarizes the Coalition for Health Funding's fiscal year 2012 funding recommendations for health agencies under the subcommittee's jurisdiction.

National Institutes of Health (NIH)

The Coalition supports \$35 billion in fiscal year 2012 for NIH, a 14.4 percent increase over the fiscal year 2011 funding level and a 10 percent increase over the President's fiscal year 2012 request. The partnership between NIH and America's scientific research community is a national investment in improving the health and quality of life of all Americans. As the primary Federal agency responsible for conducting and supporting medical research, NIH-funded research drives scientific innovation and develops new and better diagnostics, improved prevention strategies, and more effective treatments.

NIH-funded research also contributes to the Nation's economic strength by creating skilled, high-paying jobs; new products and industries; and improved technologies. More than 83 percent of NIH research funding is awarded to more than 3,000 universities, medical schools, teaching hospitals, and other research institutions, located in every State. The Nation's longstanding, bipartisan commitment to NIH has established the United States as the world leader in medical research and innovation. Other countries, such as China and India, are increasing their funding of scientific research because they understand its critical role in spurring technological advances and other innovations. If the United States is to continue to compete in a global, information-based economy, it too must continue to invest in research programs such as NIH.

Centers for Disease Control and Prevention (CDC)

The Coalition for Health Funding recommends a level of \$7.7 billion for CDC's core programs in fiscal year 2012, a 36 percent increase over fiscal year 2011 and a 31 percent increase over the President's fiscal year 2012 request. This amount is representative of what CDC needs to fulfill its core mission in fiscal year 2012; activities and programs that are essential to protect the health of the American people. CDC continues to be faced with unprecedented challenges and responsibilities, ranging from chronic disease prevention, eliminating health disparities, bioterrorism preparedness, to combating the obesity epidemic. In addition, CDC funds community programs in injury control; health promotion efforts in schools and workplaces; initiatives to prevent diabetes, heart disease, cancer, stroke, and other chronic diseases; improvements in nutrition and immunization; programs to monitor and combat environmental effects on health; prevention programs to improve oral health; prevention of birth defects; public health research; strategies to prevent antimicrobial resistance and infectious diseases; and data collection and analysis on a host of vital statistics and other health indicators. It is notable that more than 70 percent of CDC's budget flows out to States and local health organizations and academic institutions, many of which are currently struggling to meet growing needs with fewer resources.

Health Resources and Services Administration (HRSA)

The Coalition for Health Funding recommends an overall funding level of \$7.65 billion for HRSA in fiscal year 2012, a 22 percent increase over fiscal year 2011 and a 12 percent increase over the President's fiscal year 2012 request. HRSA operates programs in every State and thousands of communities across the country. It is a national leader in providing health services for individuals and families, serving as a health safety net for the medically underserved.

Over the past several years, HRSA has received mostly level funding, undermining the ability of its successful programs to grow. Additionally, the deep cuts made to the agency in the final fiscal year 2011 continuing resolution will likely have negative consequences for public health. Therefore, the requested minimum level of funding for fiscal year 2012 is critical to allow the agency to carry out critical public health programs and services that reach millions of Americans, including developing the public health and healthcare workforce; delivering primary care services through community health centers; improving access to care for rural communities; supporting maternal and child healthcare programs; providing healthcare to people living with HIV/AIDS; and many more. However, much more is needed for the agency to achieve its ultimate mission of ensuring access to culturally competent, quality health services; eliminating health disparities; and rebuilding the public health and healthcare infrastructure.

Substance Abuse and Mental Health Services Administration (SAMHSA)

The Coalition for Health Funding recommends an overall funding level of \$3.671 billion for SAMHSA in fiscal year 2012, an 8.6 percent increase over fiscal year 2011 and an 8.4 percent increase over the President's fiscal year 2012 request. According to recent results from a national survey conducted by SAMHSA, 45.1 million American adults in the United States have experienced mental illness over the past year. However, only two-thirds of adults in the United States with mental illness in the past year received mental health services.

In fact, suicide claims over 34,000 lives annually, the equivalent of 94 suicides per day; one suicide every 15 minutes. In the past year, 8.4 million adults aged 18 or older thought seriously about committing suicide, 2.3 million made a suicide plan, and 1.1 million attempted suicide. The funding for community mental health services from SAMHSA has never been more critical especially in light of the \$2.2 billion reduction in State mental health funding for programs serving this vulnerable population.

Agency for Healthcare Research and Quality (AHRQ)

The Coalition for Health Funding recommends an overall funding level of \$405 million for AHRQ in fiscal year 2012, a 9 percent increase over fiscal year 2011 and a 10 percent increase over the President's fiscal year 2012 request. AHRQ funds research and programs at local universities, hospitals, and health departments that improve healthcare quality, enhance consumer choice, advance patient safety, improve efficiency, reduce medical errors, and broaden access to essential services—transforming people's health in communities in every State around the Nation. Specifically, the science funded by AHRQ provides consumers and their healthcare professionals with valuable evidence to make the right healthcare decisions for themselves and their families. AHRQ's research also provides the basis for protocols that reduce hospital-acquired infections, and improve patient confidence, experiences, and outcomes.

The Coalition for Health Funding appreciates this opportunity to provide its fiscal year 2012 discretionary health funding recommendations and looks forward to working with the Subcommittee in the coming weeks and months.

PREPARED STATEMENT OF THE COALITION FOR HEALTH SERVICES RESEARCH

The Coalition for Health Services Research (Coalition) is pleased to offer this testimony regarding the role of health services research in improving our Nation's health. The Coalition's mission is to support research that leads to accessible, affordable, high-quality healthcare. As the advocacy arm of AcademyHealth, the Coalition represents the interests of more than 4,000 scientists and policy experts throughout the country and 160 organizations that produce and use research that improves health and healthcare. We advocate for the funding to support health services research and health data; better access to data and information to use in producing this research; and more transparent dissemination of the results of this research.

Health services research studies how to make the healthcare system work better and deliver improved outcomes for more people, at great value. These scientific findings improve healthcare by informing patient and healthcare provider choices; enhancing the quality, efficiency, and value of the care patients receive; and improving patients' access to care. Health services research both uncovers critical challenges confronting our Nation's healthcare system, and seeks ways to address them. For example, health services research tells us:

- Only 55 percent of adults receive recommended care and 47 percent of children receive indicated care (McGlynn et al, 2003; Mangione-Smith et al, 2007).
- The increased prevalence of obesity is responsible for almost \$40 billion of increased medical spending through 2006, including \$7 billion in Medicare prescription drug costs (Finkelstein, 2009).
- How hospitals were able to achieve more than 60 percent reduction in rates of bloodstream infections in very sick patients (Pronovost et al, 2006).
- More than 83,000 excess deaths each year could be prevented in the United States if the health disparities could be eliminated (Satcher et al, 2005).
- The percentage of heart attack patients receiving needed angioplasties within the recommended 90 minutes of arriving at the hospital improved from just 42 percent in 2005 to 81 percent by 2008 (Agency for Healthcare Research and Quality, 2011).

The primary economic rationale for a Government role in funding health services research is that the private market would not adequately supply for it, since the

full economic value of the evidence is unlikely to accrue solely to its discoverer. Like any corporation making sure it is developing and providing high quality products through R&D, the Federal Government has a responsibility to get the most out of every taxpayer dollar it spends on Federal health programs—Medicare, Medicaid, veterans' and service members' healthcare—by funding research that helps enhance their performance.

Finding new ways to get the most out of every healthcare dollar is critical to our Nation's long-term fiscal health. Funding for research on the quality, value, and organization of the health system will deliver real savings for the Federal Government, employers, insurers, and consumers. Research into the merits of different policy options for delivery system transformation, patient-centered quality improvement, community health, and disease prevention offers policymakers in both the public and private sectors the information they need to improve quality and outcomes, identify waste, eliminate fraud, increase efficiency and value, and promote personal responsibility.

Despite the positive impact health services research has had on the U.S. healthcare system, and the potential for future improvements in quality and value, the United States spends less than 1 cent of every healthcare dollar on this research; research that can help Americans spend their healthcare dollars more wisely and make more informed healthcare choices.

The Coalition for Health Services Research greatly appreciates the subcommittee's efforts to increase the Federal investment in health services research and health data. We respectfully ask that the subcommittee further strengthen capacity of health services research to address the pressing challenges America faces in providing access to high-quality, efficient care for all its citizens. The following list summarizes the Coalition's fiscal year 2012 funding recommendations for agencies that support health services research and health data under the subcommittee's jurisdiction.

Agency for Healthcare Research and Quality (AHRQ)

AHRQ funds research and programs at local universities, hospitals, and health departments that improve healthcare quality, enhance consumer choice, advance patient safety, improve efficiency, reduce medical errors, and broaden access to essential services—transforming people's health in communities in every State around the Nation. The science funded by AHRQ provides consumers and their healthcare professionals with valuable evidence to make the right healthcare decisions for themselves and their families. AHRQ's research also provides the basis for protocols that prevent medical errors and reduce hospital-acquired infections, and improve patient confidence, experiences, and outcomes in hospitals, clinics, and physician offices.

The Coalition joins the Friends of AHRQ—an alliance of more than 250 health professional, research, consumer, and employer organizations that support the agency—in recommending an overall funding level of \$405 million for AHRQ in fiscal year 2012, a 9 percent increase over fiscal year 2011 and a 10 percent increase over the President's fiscal year 2012 request. Within the funding provided to AHRQ, the Coalition recommends that the subcommittee support:

- A Breadth of Research Topics.*—During the last decade, AHRQ's research portfolio has focused predominantly on patient safety and healthcare quality. There has been less investment in research that provides evidence to improve the efficiency and value of the healthcare system itself. The Coalition is grateful to the subcommittee for its leadership in building a more balanced research agenda at AHRQ, and requests continued support for all aspects of research outlined in AHRQ's statutory mission, including the ways in which healthcare services are organized, delivered, and financed.
- Innovation through Competition.*—Many of the sentinel studies that have changed the face of health and healthcare in the United States—diagnosis-related groups for hospital payments, check-lists for improved patient safety, geographic variation in healthcare, re-hospitalizations among Medicare beneficiaries—are the result of ingenuity on the part of investigators and rigorous, scientific competition. Federal support for innovative approaches to problem solving increases opportunities for constructive competition and creative solutions. The Coalition is grateful to the subcommittee for its leadership in recognizing the value of investigator-initiated research at AHRQ and requests sustained momentum for these competitive, innovative grants that advance discovery and the free marketplace of ideas.
- The Next Generation of Researchers.*—At the direction of the subcommittee, AHRQ has doubled its investment in training grants for the next generation of researchers. Still, training grants for new researchers—both physicians and

non-physicians—fall far short of what is needed to meet growing public and private sector demands for health services research. The Coalition appreciates the subcommittee's continuing support of the next generation of researchers and requests that funding for training grants be increased to ensure America stays competitive in the global research market.

—*Research Translation and Dissemination.*—Health services research has great potential to improve health and healthcare when widely used by patients, providers, and policymakers. The Coalition recommends that the subcommittee support AHRQ's research translation and dissemination activities, including patient forums, practice-based research centers, and learning networks. These programs are designed to move the best available research and decisionmaking tools into healthcare practice and thus enhance patient choice and improve healthcare delivery.

Centers for Disease Control and Prevention (CDC)

The National Center for Health Statistics (NCHS) is the Nation's principal health statistics agency. Housed within CDC, NCHS provides critical data on all aspects of our healthcare system through data cooperatives and surveys that serve as a gold standard for data collection around the world. The Coalition appreciates the subcommittee's leadership in securing steady and sustained funding increases for NCHS in recent years. Such efforts have allowed NCHS to reinstate some data collection and quality control efforts, continue the collection of vital statistics, and enhance the agency's ability to modernize surveys to reflect changes in demography, geography, and health delivery.

We join the Friends of NCHS—a coalition of more than 250 health professional, research, consumer, industry, and employer organizations that support the agency—in endorsing the President's fiscal year 2012 request of \$162 million, a funding level that will build on previous investments and put the agency on track to become a fully functioning, 21st century, national statistical agency.

The Patient Protection and Affordable Care Act recognizes the need for linking the medical care and public health delivery systems by authorizing a new CDC research program to study public health systems and service delivery. If funded in fiscal year 2012, this program will identify effective strategies for organizing, financing, and delivering public health services in real-world community settings by, for example, comparing State and local health department structures and systems in terms of effectiveness and costs. The Coalition urges you to appropriate \$35 million in fiscal year 2012 for Public Health Services and Systems Research at CDC, enabling us to study ways to improve the efficiency and effectiveness of public health service delivery.

National Institutes of Health (NIH)

NIH reports that it spent \$1.1 billion on health services research in fiscal year 2010—roughly 3.6 percent of its entire budget—making it the largest Federal sponsor of health services research. For fiscal year 2012, the Coalition joins the Ad Hoc Group for Medical Research in requesting \$35 billion for NIH in fiscal year 2012, which would, based on historical funding levels, provide roughly \$1.3 billion for the agency's health services research portfolio. The Coalition believes that NIH should increase the proportion of its overall funding that goes to health services research to ensure that discoveries from clinical trials are effectively translated into health services. We also encourage NIH to foster greater coordination of its health services research investment across its institutes.

Centers for Medicare and Medicaid Services (CMS)

Steady funding reductions for the Office of Research, Development and Information have hindered CMS's ability to meet its statutory requirements and conduct new research to strengthen public insurance programs—including Medicare, Medicaid, and the Children's Health Insurance Program—which together cover nearly 100 million Americans and comprise almost half of America's total health expenditures. As these Federal entitlement programs continue to pose significant budget challenges for both Federal and State governments, it is critical that we adequately fund research to evaluate the programs' efficiency and effectiveness and seek ways to manage their projected spending growth.

The Coalition supports an fiscal year 2012 base funding level of \$40 million for CMS's discretionary research and development budget. This funding is a critical down payment to help CMS restore research to evaluate its programs, analyze pay for performance and other tools for updating payment methodologies, and further refine service delivery methods.

In conclusion, the accomplishments of health services research would not be possible without the leadership and support of this subcommittee. Health services re-

search will continue to yield valuable scientific evidence in support of improved quality, accessibility, and affordability of healthcare. We urge the subcommittee to accept our fiscal year 2012 funding recommendations for the Federal agencies funding health services research and health data.

If you have questions or comments about this testimony, please contact our Washington, DC, representative, Emily Holubowich at eholubowich@dc-crd.com.

PREPARED STATEMENT OF THE COALITION FOR INTERNATIONAL EDUCATION

Mr. Chairman and Members of the Subcommittee: We are pleased to submit the views of the Coalition for International Education on fiscal year 2012 funding for the Higher Education Act, Title VI and the Mutual Educational and Cultural Exchange Act, Section 102(b)(6), commonly known as Fulbright-Hays. The Coalition for International Education consists of over 30 national higher education organizations with interest in the U.S. Department of Education's international and foreign language education programs. The Coalition represents the Nation's 3,300 colleges and universities, and organizations encompassing various academic disciplines, as well as the international exchange and foreign language communities.

We express our deep appreciation for the Subcommittee's long-time support for the U.S. Department of Education's premier international and foreign language education programs noted above. We recognize the difficult decisions Congress and the Administration faced on education spending cuts for the remainder of fiscal year 2011, and now face for fiscal year 2012. However, we are deeply concerned over the severe and disproportionate \$50 million or 40 percent cut to the Title VI/Fulbright-Hays programs under H.R. 1473, the final fiscal year 2011 Continuing Resolution agreement. Title VI/Fulbright-Hays contain 14 small "pipeline" programs, 12 of which are under \$20 million. A cut of this magnitude will seriously weaken our Nation's world-class international education capacity, which has taken decades to build and would be impossible to easily recapture. Among the first casualties likely will be the high-cost, low-enrollment critical language programs needed for national security, such as Pashto or Urdu.

Today we strongly urge the Appropriations Committee to safeguard these programs by providing funding for them that is equal to their fiscal year 2010 funding levels in the fiscal year 2012 appropriations bill. For the International and Foreign Language Studies account, we urge a total of \$125.881 million, which includes \$108.360 million for Title VI-A&B; \$15.576 million for Fulbright-Hays 102(b)(6); and \$1.945 million for the Institute for International Public Policy, Title VI-C.

After 9/11, Congress began a decade of enhancements to Title VI/Fulbright because of the sudden awareness of an urgent need to improve the Nation's in-depth knowledge of world areas and transnational issues, and fluency of U.S. citizens in foreign languages. Unfortunately these gains and many program enhancements on strategic world areas will be eliminated unless funding is restored to fiscal year 2010 levels.

We believe maintaining a strong Federal role in these programs is critical to supporting our Nation's long-term national security, global leadership, economic competitiveness capabilities, as well as mutual understanding and collaboration around the world. Successful U.S. engagement in these areas, at home or abroad, relies on Americans with global competence, including foreign language skills and the ability to understand and function in different cultural and business environments.

Background and Federal Role

In 1958 at the height of the cold war, Congress created NDEA-Title VI out of a sense of crisis about U.S. ignorance of other countries and cultures. Fulbright 102(b)(6) was created in 1961 and placed with Title VI to provide complementary overseas training. These programs have served as the lynchpin for producing international specialists for more than five decades, and continue to do so. Improving over time to address new global challenges and expanded needs across the Nation's workforce, 14 Title VI/Fulbright-Hays programs support activities to improve capabilities and knowledge throughout the educational pipeline, from K-12 through the graduate levels and advanced research, with emphasis on the less commonly-taught languages and areas, such as China, Russia, India and the Muslim world. Today they are the Federal Government's most comprehensive programs supporting the development of high quality national capacity in international, foreign language and business education and research. A March 2007 report by the National Academies of Sciences (NAS) concluded, "Title VI/Fulbright-Hays serve as our Nation's foundational programs for building U.S. global competence."

This Federal-university partnership ensures resources and knowledge are available to meet national needs that are not priorities of individual States or universities. Federal resources are essential incentives to develop and sustain high-cost programs in the less commonly-taught languages and world areas, and provide extensive outreach and collaboration among educational institutions, government agencies, and corporations. Most of these programs would not exist without Federal support, especially at a time when State/local governments and institutions of higher education are financially strapped.

Why Investing in Title VI/Fulbright-Hays Is Important

The NAS reported in 2007: “A pervasive lack of knowledge about foreign cultures and foreign languages in this country threatens the security of the United States as well as its ability to compete in the global marketplace and produce an informed citizenry.”

Government Needs.—The quantity, level of expertise, and availability of U.S. personnel with high-level expertise in foreign languages, cultures, and political, economic and social systems throughout the world do not match our national strategic needs at home or abroad. Some 80 Federal agencies depend in part on proficiency in more than 100 foreign languages; in 1985, only 19 agencies identified such requirements.

“Foreign language skills are vital to effectively communicate and overcome language barriers encountered during critical operations and are an increasingly key element to the success of diplomatic efforts, military operations, counterterrorism, law enforcement and intelligence missions, as well as to ensure access to Federal programs and services to Limited English Proficient (LEP) populations within the United States.” *David Maurer Testimony on Foreign Language Capabilities. Department of Homeland Security, Defense, and State Could Better Assess their Foreign Language Needs and Capabilities and Address Shortfalls, GAO, July 2010*

“As of October 31, 2008, 31 percent of Foreign Service officers in overseas language-designated positions (LDP) did not meet both the foreign languages speaking and reading proficiency requirements for their positions. State continues to face foreign language shortfalls in regions of strategic interest—such as the Near East and South and Central Asia, where about 40 percent of officers in LDPs did not meet requirements. Past reports by GAO, State’s Office of the Inspector General, and others have concluded that foreign language shortfalls could be negatively affecting U.S. activities overseas.” *Comprehensive Plan Needed to Address Persistent Foreign Language Shortfalls, GAO, September 2009.*

Workforce Needs.—National security is increasingly linked to commerce, and U.S. business is widely engaged around the world with joint ventures, partnerships, and economic linkages that require its employees to have international expertise both at home and abroad.

“Most of the growth potential for U.S. businesses lies in overseas markets. Already, one in five U.S. manufacturing jobs is tied to exports. Foreign consumers, the majority of whom primarily speak languages other than English, represent significant business opportunities for American producers, as the United States is home to less than 5 percent of the world’s population. American companies lose an estimated \$2 billion a year due to inadequate cross-cultural guidance for their employees in multicultural situations.” *Education for Global Leadership, Committee for Economic Development, 2006.*

Education Needs.—Education institutions at all levels are challenged to keep up with rapidly expanding 21st century needs for global competence.

- Although higher education foreign language enrollments have increased and diversified over the past decade, according to the Modern Language Association’s 2010 survey, enrollments are only 8.7 percent of total student enrollments, well behind the 1960 high point of 16 percent.
- Only 5 percent of all higher education students taking foreign languages study non-European languages spoken by roughly 85 percent of the world’s population.
- Less than 2 percent of students in U.S. postsecondary education study abroad, and only about half studied outside Western Europe. Yet, an educational experience abroad is an essential element for achieving foreign language fluency, learning how to function in other cultures, and developing mutual understanding with others beyond our borders.
- U.S. educational institutions from K–16 face a shortage of teachers and faculty with international knowledge and expertise across the professions and across

types of higher education institutions. This problem is especially acute for foreign language teachers of the less commonly taught languages.

What Title VI/Fulbright-Hays Programs Do

Title VI/Fulbright programs produce U.S. experts, prepare Americans for the global workplace, and generate knowledge on the foreign languages and business, economic, political, social, cultural and regional affairs of other countries and world areas. Grantees also engage in extensive outreach and collaboration across the educational spectrum, and with business, government, the media and the general public. Title VI-funded centers are relied upon for their expertise by Federal agencies, corporations, and local school districts. Their many accomplishments include the following:

Language and Culture

Through several pipeline programs, Title VI institutions provide the major, and often the only, source of national expertise and research on non-European countries and their languages.

Title VI institutions account for 21 percent of undergraduate enrollment and 56 percent of graduate enrollment in the less commonly taught languages (LCTLs) such as Arabic and Chinese. For the least commonly taught languages such as Pashto and Urdu, Title VI institutions account for 49 percent of undergraduate and 78 percent of graduate enrollments.

Title VI institutions provide instruction and R&D in over 130 languages and in all world areas, and have the capacity to teach over 200 languages. Because of the high cost per student, many of these languages would not be taught on a regular basis but for Title VI/Fulbright support. In contrast, the Defense Language Institute (DLI) and the Foreign Service Institute (FSI) together offer instruction in only 75 LCTLs.

Title VI/Fulbright programs support advanced research abroad in international, area and language studies—such as through the Fulbright programs and overseas research centers—that otherwise would have few or no other funding sources.

Title VI programs support the development and maintenance of world class digital information resources in international, area and foreign language studies—using modern technologies for accessibility—that exist nowhere else in the world.

Title VI/Fulbright programs provide opportunity and access to all types of institutions of higher education, including minority-serving institutions, community colleges, and small and medium-sized 4-year institutions. With seed funding from the Undergraduate International Studies and Foreign Language, Institute for International Public Policy and Fulbright programs, training, fellowship, scholarship and study abroad opportunities are provided to students, faculty and administrators.

With enhancements provided by Congress between 2000–08, Title VI National Resource Centers increased annual job placements in key sectors. 2008 placements and percent increase over 2000: Federal Government 1,515 (+32 percent), U.S. military 552 (+20 percent), international organizations 1,567 (+22 percent), and higher education 3,414 (+51 percent).

During this same period, the NRCs have seen triple digit increases in courses and enrollments in critical languages. Between 2000 and 2008, enrollments in Arabic increased from 5,218 to 16,721, in Chinese from 9,637 to 23,724, in Persian from 1,231 to 3,878, in Turkish from 594 to 1,602, and in Urdu from 221 to 904.

Examples of renowned graduates include Secretary of Defense Robert Gates, General John Abizaid, former Ambassador to Russia James Collins, advisor to six Secretaries of State Aaron David Miller, and NY Times Pulitzer prize-winning journalist Anthony Shadid.

International Business

Title VI supports two important programs that internationalize business education, train Americans for the global workplace, and help U.S. small and mid-size businesses engage emerging markets: Centers for International Business Education and Research (CIBERs) and Business and International Education (BIE).

CIBERs offer training at all levels of education in all 50 States, including training for managers already active in the workforce, and research on cutting edge issues affecting the U.S. business environment, the Nation's global economic competitiveness and homeland security.

Before these programs were established, few business education programs in the United States incorporated a global dimension. Over 2 million students have taken international business courses through CIBER programs and over 160,000 faculty have gained international business and cultural expertise through faculty programs, domestically and abroad.

Over 42,000 language faculty have participated in over 900 international business language workshops, and 4.5 million students across the United States have benefited from enhanced commercial foreign language instruction.

Outreach

Title VI/Fulbright grantees provide access to international knowledge to other institutions of higher education, government, business, K–12 and the public through web resources, seminars, training and other means. Many educators, government agencies, nonprofit groups and corporations depend on these resources. Without Title VI/Fulbright funding, this outreach would disappear.

Title VI National Resource Centers provide training and consultation for foreign language and area staff in many government agencies. For example, the U.S. Army Foreign Area Officer (FAO) Program sends its officers to Title VI centers for their M.A. in language and area studies training and has done so since the inception of the FAO program three decades ago.

Title VI Language Resource Centers (LRC) train an estimated 2,000 teachers annually, and develop resources in critical languages used by educators and government agencies. For example, an LRC recently developed a free iPad app that provides tutorials in Pashto for U.S. soldiers in Afghanistan.

CIBER and BIE grantees work closely with the U.S. Department of Commerce and with the local District Export Councils on export development. In response to President Obama's 2010 National Export Initiative (NEI), the CIBERs continue to expand the global knowledge base of U.S. companies, enabling and assisting them to export their goods and services especially to the BRIC and other emerging markets. By enabling small and mid-sized U.S. business to increase exports, CIBER/BIE activities support job creation in America and reduction of the trade deficit.

Title VI grantees also work extensively with minority-serving institutions of higher education, community colleges and K–12 on language and culture programs, as well as with the media to promote citizen understanding of complex global issues.

Clearly, this Federal-higher education partnership pays dividends that vastly outweigh the small 0.2 percent investment within the Department of Education's budget.

PREPARED STATEMENT OF THE COALITION FOR WORKFORCE SOLUTIONS

I represent The Coalition for Workforce Solutions (CWS), a national organization exclusively representing employers, workforce development providers, vendors and service organizations that operate and utilize One-Stop Career Centers, Temporary Assistance for Needy Families initiatives, career and technical education programs and workforce investment services. Members of CWS are proud to play a role in our workforce system as it promotes economic growth while giving unemployed, underemployed and disadvantaged workers an opportunity to gain new skills.

Today, while the Nation faces many complex challenges in light of mass layoffs and business realignments, the private sector is showing signs of recovery and businesses new and old need increased assistance in addressing their workforce needs. And our national network of WIA supported workforce services is in a unique position not only to train workers for economic recovery, but to match large and small employers with qualified workers in advanced manufacturing, healthcare, energy and other high-growth sectors. As the economy grows, our workforce system should be maintained and strengthened, not reduced or targeted for elimination.

We understand the budget issues and the need for debt reduction. We are confident that through integration of workforce services there is the capacity to maintain the existing level of service to the job seekers and employers. We look to the State of Florida and Texas as the model of integrated services for replication nationwide. This will ensure our workforce development and job-training system continues its vital support for businesses of all sizes to create and retain jobs, provide needed skills and transition assistance to workers, and enhance economic growth through the private sector in thousands of communities around the country.

Our Nation's workforce systems funded through WIA have become critical partners in regional economic development efforts—from directly supporting efforts to recruit new businesses (by offering access to skilled workers and employment and training incentives), to saving money for local businesses as they begin to rehire workers. The programs also assist businesses to avert layoffs through skills upgrading, and support businesses that are closing or downsizing. These partnerships with employers and economic development services are critical to helping businesses survive and contribute to regional economic growth and prosperity. Now is not the time

to take away these vital services when economic growth is paramount to our recovery and competitiveness.

WIA has experienced a 234 percent increase in demand for services since the onset of the recession and demand remains steady as the economy grows. It is easy to see why this is so: the one-stop system supported with WIA funds fosters community partnerships that drive job creation and economic recovery efforts while also providing vital labor market information, skills assessments, career guidance, counseling, employment assistance, support and training services to jobseekers and workers who need help in getting good jobs.

In every State and region, the workforce system addresses the needs of business so that local companies can remain competitive. By building relationships with community development organizations and local officials, businesses are provided with a collaborative network of support that is best-suited to the needs of employers. Only this system can provide businesses with the resources they can use to survive and thrive in this difficult economic time.

In fact, the workforce system is the only system of its kind to engage employers and address the kind of compelling challenges that business face in the following areas:

- Reducing turnover in entry level occupations in high growth industries such as healthcare through early immersion and career ladder programs.
- Finding the talent that advanced manufacturing companies need to compete by training workers in new skills and providing the next generation of workers a path to the modern workforce.
- Supporting economic development and business attraction activities so that new employers and manufacturers get assistance in determining local infrastructure, specific fits for training needs, and whatever it takes to be successful.
- Preparing youth in high demand IT careers as well as providing soft skills training, job search preparation, coaching and the life transforming skills that businesses need to develop a stable, high-quality workforce.
- Improving hiring efficiency such that employers improve their application conversion rate by 50 percent through collaborative partnerships with the workforce system that produce qualified candidates with the right skill-sets, dedication and motivation that employers need.

Businesses as well as jobseekers and workers benefit from WIA services. Research indicates that the workforce system produces a high return on investment. Last year, over 8 million job-seekers utilized the workforce system and over 4.3 million of them got jobs. While this is less than the normal 80 to 85 percent placement rate common in stronger economic times, the recent job environment had four jobseekers for every one vacancy. However, when jobs were simply not available, the system placed many of the unemployed in education and training programs that will lead to good new jobs.

The system is also effective. According to an Upjohn Institute Study, positive and statistically significant results were found for WIA Adult Program participants and for the Dislocated Worker Program. Furthermore, these employment and training services were shown to reduce reliance on public assistance. The average duration on TANF public assistance also was reduced by several percentage points for those participating in WIA or TANF welfare-to-work programs. One can conclude from a variety of studies that WIA training services raise employment rates and earnings while reducing reliance on TANF.

Many CWS members are private businesses that struggle everyday with budgets, so we can appreciate the need to make tough decisions. Since job creation is a priority for the Congress and since workers pay taxes and reduce pressure on public programs, maintaining support for the workforce system should remain a top priority. The workforce system is a critical partner in the Nation's economic recovery as it trains and retrain workers to meet the demands of our changing economy. In our judgment, this system is essential to addressing the employment needs of the more than 14 million unemployed in this country—we cannot afford to lose this valuable resource.

Nevertheless, Congress recently reduced WIA's three State/local program sections by about \$307 million below the fiscal year 2010 levels enacted in Public Law 111-117. Overall, the last CR provides about \$2.8 billion for job-training State grants for adult employment, youth activities, and dislocated workers. The more than \$1 billion in reductions to key job training and education programs equate to more than 10 percent less than fiscal year 2010 enacted levels.

While funding for Program Year 2011 is now set, the spending agreement covers only the first quarter of the next WIA program year ending September 30, 2011. Funding for the final three quarters will be contained in the fiscal year 2012 appropriations.

Many WIA programs have received funding reductions in real dollar terms in recent years—these programs are significantly underfunded already relative to their mission. Congress should use the findings of duplication and overlap in workforce programs not to make further reductions but rather to work with the House Education and Workforce Committee to achieve better coordination and integration of services.

Despite the significant cuts in the latest CR, the bill represents substantial progress for thousands of jobseekers and employers across the country who informed their policymakers on the critical benefits of our workforce system. We are encouraged to see that Congress has rejected the severest cuts proposed early this year and we hope there is a more accurate picture for fiscal year 2012 emerging of how WIA programs help employers find qualified workers and train workers for new careers.

In short, CWS will work with Members of this Committee, the authorizing committees and other Members of Congress as they consider policies to better align planning and service delivery, and strengthen the overall system. As issues develop, there will be discussions about expectations for the future of the workforce system. Here are some issues of primary importance to CWS:

- Enhancing WIA accountability and driving high performance;
- Empowering Workforce Investment Boards to play a strategic role that promotes coordination and integration of services across federally funded systems;
- Serving disadvantaged and underserved populations; and
- Sharing and promoting best practices throughout the system.

CWS believes that WIA's core services and training have paid off in terms of higher employment rates and improved earnings for dislocated workers, the unemployed and disadvantaged youth and adults. As Members of the Committee examine the facts concerning WIA services, we trust that they will agree that the workforce system provides vital services to businesses and jobseekers. Thank you for your consideration of my testimony.

PREPARED STATEMENT OF THE COALITION FOR THE ADVANCEMENT OF HEALTH
THROUGH BEHAVIORAL AND SOCIAL SCIENCE RESEARCH

Mr. Chairman and Members of the Subcommittee, the Coalition for the Advancement of Health Through Behavioral and Social Science Research (CAHT-BSSR) appreciates and welcomes the opportunity to comment on the fiscal year 2012 appropriations for the National Institutes of Health (NIH). CAHT-BSSR includes 14 professional organizations, scientific societies, coalitions, and research institutions concerned with the promotion of and funding for research in the social and behavioral sciences. Collectively, we represent more than 120 professional associations, scientific societies, universities, and research institutions.

CAHT-BSSR would like to thank the Subcommittee and the Congress for their continued support of the NIH. Strong sustained funding is essential to national priorities of better health and economic revitalization. Providing adequate resources in fiscal year 2012 that allow the NIH to keep up with the rising costs of biomedical, behavioral, and social sciences research will help NIH begin to prepare for the era beyond recovery. We recognize that these are difficult times for our Nation, but at the same time, it is essential that funding in fiscal year 2012 and beyond allow the agency to resume steady, sustainable growth of the foundation of knowledge built through NIH-funded research at more than 3,000 universities, medical schools, teaching hospitals, and research institutions. CAHT-BSSR supports the NIH fiscal year 2012 request of \$31.7 billion, at a minimum, and joins the Ad Hoc Group for Medical Research in its request for \$35 billion in funding for NIH in fiscal year 2012.

NIH Behavioral and Social Sciences Research.—NIH supports behavioral and social science research throughout most of its 27 institutes and centers. The behavioral and social sciences regularly make important contributions to the well-being of this Nation. Due in large part to the behavioral and social science research sponsored by the NIH, we are now aware of the enormous contribution behavior makes to our health. At a time when genetic control over diseases is tantalizingly close but not yet possible, knowledge of the behavioral influences on health is a crucial component in the Nation's battles against the leading causes of morbidity and mortality: obesity, heart disease, cancer, AIDS, diabetes, age-related illnesses, accidents, substance use and abuse, and mental illness.

As a result of the strong congressional commitment to the NIH in years past, our knowledge of the social and behavioral factors surrounding chronic disease health outcomes is steadily increasing. The NIH's behavioral and social science portfolio

has emphasized the development of effective and sustainable interventions and prevention programs targeting those very illnesses that are the greatest threats to our health, but the work is just beginning.

From global warming to unlocking the secrets of memory; from self destructive behavior, such as addiction, to lifestyle factors that determine the quality of life, infant mortality rate and longevity; the grandest challenge we face is understanding the brain, behavior, and society. Nearly 125 million Americans are living with one or more chronic conditions, like heart disease, cancer, diabetes, kidney disease, arthritis, asthma, mental illness and Alzheimer's disease. Significant factors driving the increase in healthcare spending in the United States are the aging of the U.S. population, and the rapid rise in chronic diseases, many of which can be caused or exacerbated by behavioral factors. Obesity may be the result of sedentary behavior and poor diet; and addictions, resulting in health problems caused by tobacco and other drug use. Behavioral and social sciences research supported by NIH is increasing our knowledge about the factors that underlie positive and harmful behaviors, and the context in which those behaviors occur.

CAHT-BSSR continues to applaud the Congress' and NIH's recognition that the "scientific challenges in developing an integrated science of behavior change are daunting." The agency's efforts to launch the basic behavioral and social science research trans-NIH initiative, Opportunity Network for Basic Behavioral and Social Sciences Research (OppNet), likewise, is applauded. OppNet is designed to examine the important scientific opportunities that cut across the structure of NIH and designed to look for strategic opportunities to build areas of research where there are gaps that have the potential to affect the missions of multiple institutes and centers. Research results could lead to new approaches for reducing risky behaviors and improving health.

Equally, we commend the agency's support of the "Science of Behavior Change" Common Fund Initiative included in the third cohort of research areas for the Common Fund. We agree with the goals of this Common Fund Pilot to "establish the groundwork for a unified science of behavior change that capitalizes on both the emerging basic science and the progress already made in the design of behavioral interventions in specific disease areas. By focusing basic research on the initiation, personalization, and maintenance of behavior change, and by integrating work across disciplines, this Common Fund effort and subsequent trans-NIH activity could lead to an improved understanding of the underlying principles of behavior change. This should drive a transformative increase in the efficacy, effectiveness, and (cost) efficiency of many behavioral interventions."

With the recent passage of healthcare reform legislation, there has been the accompanying and appropriate attention to the issue of personalized healthcare. CAHT-BSSR believes that personalization needs to reflect genes, behaviors, and environments. And as the agency has acknowledged with its recent support of the Science of Behavior Change initiative, assessing behavior is critical to helping individuals see how they can improve their health. It is also critical to helping healthcare systems see where to put resources for behavior change. Fortunately, the NIH acknowledges the need to focus less on finding the "magic answer" and, at the same time, recognizes that healthcare is different from region to region across the country. Full personalization needs to consider the environmental, community, and neighborhood circumstances that govern how individuals' genes and behavior will influence their health. For personalized healthcare to be realized, we need a sophisticated understanding of the interplay between genetics and the environment, broadly defined.

In fiscal year 2012, NIH priorities include establishment of the National Center for Advancing Translational Sciences (NCATS) intended to align and bring together a number of trans-NIH programs that do not have a specific disease focus in one organization. As with development of more effective drugs, surgical techniques and medical devices, the development of more powerful health-related behavioral interventions is dependent on improving the understanding of human behavior, and then translating that knowledge into new and more effective interventions with enduring effects. It is critical that the NIH support for translational research extends to translation research designed to adapt findings from basic behavioral and/or social science research to develop behavioral interventions directed at improving health-related behaviors such as adequate physical activity and nutrition, learning and learning disabilities, and preventing or reducing health-risking behaviors including tobacco, alcohol, and/or drug abuse, and unprotected sexual activity. CAHT-BSSR strongly believes that the translation of behavioral interventions is a critical part of the NCATS initiative and must be accompanied by sufficient staff expertise and resources to manage research on the translation of behavioral interventions into communities.

CAHT-BSSR applauds the NIH's recognition of a unique and compelling need to promote diversity in health-related research. The agency expects these efforts to lead to: the recruitment of the most talented researchers from all groups; an improvement in the quality of the educational and training environment; a balanced perspective in the determination of research priorities; an improved ability to recruit subjects from diverse backgrounds into clinical research; and an improved capacity to address and eliminate health disparities. Numerous studies provide evidence that the biomedical and educational enterprise will directly benefit from broader inclusion.

NIH recognizes that developing a more diverse and academically prepared workforce of individuals in STEM (science, technology, engineering, and math) disciplines will benefit all aspects of scientific and medical research and care. CAHT-BSSR applauds the agency's recognition that, to remain competitive in the 21st century global economy, the Nation must foster new opportunities, approaches, and technologies in math and science education.

This recognition extends to the need for a coordinated effort to bolster STEM education nationwide, starting at the earliest stages in education. Unfortunately, the narrow perception of "science" persists, and the social and behavioral sciences are often excluded in discussion of STEM issues and remain outside of the science education curriculum. The considerable activity on STEM education provides the opportunity to improve the recognition of social and behavioral sciences as "science."

In 2010, the NIH commissioned the Institute of Medicine (IOM) to do a study surrounding LGBT (lesbian, gay, bisexual, and transgender) health issues, research gaps and opportunities. The recently released study, *The Health of Lesbian, Gay, Bisexual, and Transgender People*, examined the current state of knowledge on LGBT health, including general health concerns and health disparities, identified research gaps and opportunities; and outlined a research agenda which reflects the most pressing areas, specifically demographic research, social influences, healthcare inequities, intervention research, and transgender-specific health needs.

NIH OFFICE OF BEHAVIORAL AND SOCIAL SCIENCES RESEARCH

The NIH Office of Behavioral and Social Sciences Research (OBSSR), authorized by Congress in the NIH Revitalization Act of 1993 and established in 1995, serves as a convening and coordinating role among the institutes and centers at NIH. In this capacity, OBSSR develops, coordinates, and facilitates the social and behavioral science research agenda at NIH; advises the NIH director and directors of the 27 institutes and centers; informs NIH and the scientific and lay publics of social and behavioral science research findings and methods; and trains scientists in the social and behavioral sciences. For fiscal year 2012, CAHT-BSSR supports a budget of \$38.2 million for OBSSR. This sum reflects the Administration's request of \$28 million for OBSSR and includes the \$10 million needed to support the NIH-wide commitment to carry out OppNet, an initiative strongly supported by the Subcommittee. The OppNet initiative has made significant progress since its start. Thus far, OppNet has awarded 35 competitive revisions to add basic science projects to existing research project grants. Eight competitive revisions to Small Business Innovation Research/Small Business Technology and Transfer projects have been awarded. OppNet has also provided the much-needed training in basic social and behavioral sciences research.

In fiscal year 2012, OBSSR intends partner with the NIH institutes and centers and other Federal agencies to fund Mobile Technology Research (mHealth) to Enhance Health. Recent advances in mobile technologies and the use of these technologies in daily life have created opportunities for research applications that were not previously possible, such as assessing behavioral and psychological states in real time. To make use of this technology as effective as possible there is a need to integrate the behavioral, social sciences, and clinical research fields. The NIH mHealth Summer Institute is designed to address the lack of integration of these fields.

Over the years, OBSSR has sponsored summer training institutes for scientists interested in social and behavioral science research areas. The interest in these training sessions have been overwhelming and have exceeded the Office's capacity to provide the opportunity for scientists and researchers to gain critical training in these areas. These institutes include training in: systems science methodology and health; randomized clinical trials involving behavioral interventions; dissemination and implementation research in health; and mobile health. The Dissemination and Implementation Research in Health training institute, for example, features a faculty of leading experts from a variety of behavioral and social science disciplines and is designed to empower scientists to conduct this research. Drawing from these disciplines, dissemination and implementation research uses approaches and methods

that in the past have not been taught comprehensively in most graduate degree programs. Given the demand for the training these institutes provide and the potential this research has for propelling the science forward, CAHT-BSSR believes that greater collaboration with the NIH institutes and centers is needed to meet the demand.

CAHT-BSSR would be pleased to provide any additional information on these issues. Below is a list of coalition member societies. Again, we thank the Subcommittee for its generous support of the National Institutes of Health and for the opportunity to present our views.

CAHT-BSSR

American Association of Geographers	Federation of Associations in Behavioral
American Educational Research Association	& Brain Sciences
American Psychological Association	National Association of Social Workers
American Sociological Association	National Communication Associations
Association of Population Centers	Population Association of America
Consortium of Social Science Associations	Society for Behavioral Medicine
Council on Social Work Education	Society for Research in Child Development
	The Alan Guttmacher Institute (AGI)

PREPARED STATEMENT OF THE COALITION OF HERITABLE DISORDERS OF CONNECTIVE TISSUE

Chairman Tom Harkin, Chairman, and Richard Ranking Member Shelby, and members of the Subcommittee: the Coalition of Heritable Disorders of Connective Tissue thanks you for the opportunity to submit testimony regarding the fiscal year 2012 budget for the National Heart, Lung and Blood Institute (NHLBI), the National Institute of Arthritis, Musculoskeletal and Skin Diseases, (NIAMS), and the NIH Office of Research Information Services/Office of Extramural Research. We are extremely grateful for the Subcommittee's strong support of the NIH, particularly as it relates to life threatening genetic disorders such as Heritable Disorders of Connective Tissue. Thanks to your leadership, we are at a time of unprecedented hope for patients with these diseases.

It is estimated that over 1 million people in the United States are affected by Heritable Disorders of Connective Tissue (HDCT). These disorders manifest themselves in many areas of the body, including the heart, eyes, skeleton, lungs and blood vessels. Connective tissue is the "glue" that holds the body together. These disorders are progressive conditions caused by genetic mutations and cause deterioration in each of these body systems. The most life-threatening are those which affect the aorta and the heart—the most disabling are orthopedic and ophthalmological.

Some 60 years ago, Victor McKusick, the "father" of modern medical genetics, described and coined the term "heritable disorders of connective tissues." These disorders included over 200 such rare disorders, among which were the Marfan syndrome, Weill-Marchesani syndrome, Ehlers-Danlos syndrome, Cutis Laxa, Osteogenesis imperfecta, the chondrodysplasias, and Pseudoxanthoma elasticum (Heritable Disorders of Connective Tissue, McKusick, Va 1972).

Awareness of these disorders has grown through the years due to collaborative research. Clues to the underlying causes of these diseases were obtained from the major manifestations found in the connective tissue and elaboration of connective tissue pathways involving identified disease genes and their protein products uncovered additional disease genes with related connective tissue manifestations. Identification of disease genes have led to surprising new information regarding important connective tissue pathways depending on the history of the particular disorder. Thus, the concept of the heritable disorders of connective tissue have reiterated and epitomized important lessons regarding how the connective tissue integrates cellular and organ function.

National Heart Lung and Blood Institute

Thanks to research funded by the NHLBI, we have seen amazing responses to HDCT disorders with cardiovascular disease. In the 1960s there was no intervention available, not even surgery for heart defects and dissection, this before the development of the "heart-lung" machine. It was not so long ago, when in the early 1960s, a 13 year old girl with Marfan syndrome was sent home from the hospital to die since there was no surgical intervention possible for her dissecting aneurysm. Early on, surgery required replacing the aortic valve with an animal's heart, further re-

search used a mechanical valve, and then came the sturdy composite graft, which became the “Cadillac” of surgical repair. Although the valve sparing method was used throughout this time, it has been continually improved to address the compromised tissue regarding longevity. Now we are seeing additional “translational” clinical trials, which look at therapies for prevention as well as surgical response. It is important to remember these amazing leaps and bounds in medical, surgical and technological advancement.

NHLBI support has been essential in promoting research collaboration. The Pediatric Heart Network, a cooperative network of pediatric cardiovascular clinical research centers, serves as a data coordinating center to promote the exchange of information to evaluate therapeutic and management strategies for children and adults with congenital and genetic heart defects.

NHLBI funded Clinical Trials in the use of Losartan have led to exciting new findings and pointed the way in future research directions. It has inspired current concepts of architectural and signaling pathways underlying the various heritable disorders of connective tissue in order to integrate these concepts in new productive ways. For example, can the recent advances in treating Marfan syndrome with TGF beta inhibitors and Losartan be applied to other heritable disorders of connective tissue? Does TGF beta signaling play pathological roles in other disorders? For another example, is there an important adhesion junction of architectural pathway that connects the vascular smooth muscle cell to the extracellular matrix? And, again: How do cell surface receptors (integrin and growth factor receptors) coordinate architectural and signaling pathways in connective tissue disorders? All pointing to future research avenues.

National Institute of Arthritis, Musculoskeletal and Skin Diseases

The collaboration of NHLBI and NIAMS has provided an even greater overview of the information gleaned from the Losartan clinical trial and a global view of these multi-system disorders. The muscular and orthopedic involvement is being addressed by the NIAMS. Through NIAMS support, there is a meeting in July, which is devoted to “Translational” avenues grown of current research progress in the understanding of heritable disorders of connective tissue. Great progress in the understanding of HDCT has been made over the past 15 years through NIAMS supported workshops on Heritable Disorders of Connective Tissue. Symposia have been convened in 1990, 1995, and 2000. In 1990 and 1995, the emphasis was on finding the genes for the various heritable disorders and understanding whether mutations could be correlated with specific phenotypes. Many of these goals have been met, due to research supported in large part by the NIAMS. In 2000, meeting themes were intentionally broader, focusing on multidisciplinary approaches and common themes in matrix biology in order to (1) promote a better understanding of pathogenesis of connective tissue disorders, (2) stimulate new collaborations between investigators, and (3) identify areas in which rapid progress could be made. In the decade since the 2000 Workshop, tremendous progress has been made, leading notably to new therapies. An example of this is Marfan syndrome, for which a clinical trial is underway to test for a therapy, which may prove to play a pivotal role in preventing heart disease. Epidermolysis bullosa is another disease—for which a research has improved prospects for new therapies, as well as for a number of other heritable disorders of connective tissue.

Research has emphasized an understanding of the role of cells in developing treatments for connective tissue disorders. The success of bone marrow transplantation in treating Epidermolysis Bullosa has called attention to this area. While connective tissue researchers have been interested in stem cell treatments—Osteogenesis imperfecta, for example—more discussion and emphasis in this area are needed.

The impact of this collaboration between these similar disease entities in heritable disorders of connective tissue continues to be of major importance. We are moving rapidly from the “bench to the patient,” from basic research to the important translational benefit of research findings to treatments which directly benefit the patient. The collaboration between the basic research and clinical studies is what we are able to focus on in these disorders for the benefit of all disease groups.

NIH/Office of Research Information Services/Office of Extramural Research—Reporter

The National Institute of Health (NIH) has established the NIH RePorter, or research/condition/disease category (RCDC) which provides easy retrieval of information on scientific projects and studies. This excellent new tool provides information on research results, expediting access and the avoidance of duplication and is located in the Office of Research Information Services/Office of Extramural Research. It provides access to research information on all disease groups. We urge the inclu-

sion of the category “Heritable Disorders of Connective Tissue” (HDCT) in order to facilitate the exchange of information in the research community of these similar disorders.

What is so important about the study of these disorders is their very complexity—with genetic origins, requiring basic science for understanding, and clinical trials in order to maximize the translational advantages of this research. The mutations of HDCT affect all body systems and require particular depth of investigation. This very complexity informs the researcher, as well as contributes to the understanding of other more common disorders. Research on these disorders in all of the body systems, will “spill” over into research into many of the categories identified in both the short range and the long range strategic plans for NHLBI and NIAMS, and provide benefits for many diseases beyond the scope of HDCT.

About the Coalition of Heritable Disorders of Connective Tissue (CHDCT)

The CHDCT is a nonprofit voluntary health organization founded in 1989, dedicated to saving lives and improving the quality of life for individuals and families affected by any 1 of the over 200 Heritable Disorders of Connective Tissue. The mission is to raise awareness of these disabling and often deadly disorders and to support and promote research and collaboration between researchers in the field.

We thank you for this opportunity to thank the Committee for its past support and to voice the interests and concerns of the CHDCT member organizations relating to future priorities of NHLBI and the NIAMS.

PREPARED STATEMENT OF THE COMMISSIONED OFFICERS ASSOCIATION OF THE U.S.
PUBLIC HEALTH SERVICE

On behalf of the Commissioned Officers Association of the U.S. Public Health Service, Inc. (COA), and in the context of the President’s fiscal year 2012 budget request, I respectfully ask to submit this statement for the record. I speak for our Association’s members, all of whom are active-duty or retired officers of the Commissioned Corps of the U.S. Public Health Service (USPHS).

We respectfully make two funding requests: Support for a pilot program to recruit and train public health doctors, dentists, and nurses for careers in the Commissioned Corps of the U.S. Public Health Service (USPHS), and support for the establishment of a USPHS Ready Reserve component. Congress authorized both programs last year, and directed the Department of Health and Human Services to implement them.

U.S. PUBLIC HEALTH SCIENCES TRACK

First, we ask this subcommittee to approve \$30 million to establish a scaled-back version of the public health workforce training program for would-be USPHS officers that was authorized by the Patient Protection and Affordable Care Act (Public Law 111–148). This pilot program would be based first at the Uniformed Services University of the Health Sciences (USUHS), which is the dedicated medical school and research institute for uniformed services personnel (Army, Navy, Air Force, Public Health Service.) Additional schools would be selected by the Surgeon General as provided for in law.

Background and Rationale

USPHS health professionals serve the health needs of the Nation’s most underserved populations. They also serve side-by-side with Armed Forces personnel at home and abroad, on joint training missions, and even in forward operating bases in combat zones. USPHS psychiatric nurses have treated injured soldiers under fire in Afghanistan. At home, USPHS psychologists and other mental health specialists have been detailed to the military to treat returning soldiers and Marines suffering from traumatic brain injury and post-traumatic stress disorder. The PHS Commissioned Corps is a public health and national security force multiplier.

The original proposal, set forth in Section 5315 of PPACA, would have established a “U.S. Public Health Sciences Track” providing for a total of 850 annual scholarships for medical, dental, nursing, and public health students who commit to public service careers in the USPHS. Such a program would be the first of its kind, the first dedicated pipeline into the USPHS Commissioned Corps.

Funding

The PPACA provisions authorizing the U.S. Public Health Sciences Track also identified an existing source of funds within the Department of Health and Human Services (DHHS). Support was to come from the Public Health and Social Services Emergency Fund. The law directed the DHHS Secretary to “transfer from the Public

Health and Social Services Emergency Fund such sums as may be necessary" (Sec. 274). The language in the PPACA is clear and straightforward, but, for reasons unknowable to this Association, the directed funding transfer has not occurred.

USPHS READY RESERVE

This Association's second request is for sufficient funding to establish a Ready Reserve component within the USPHS Commissioned Corps. We ask the subcommittee to appropriate \$12,500,000 annually through fiscal year 2014 for this purpose. Creation of a USPHS Ready Reserve was approved by Congress last year as part of the PPACA (Section 5210). Lawmakers wanted to bring the structure of the USPHS into line with that of its sister services in the Department of Defense; that objective is articulated several times in the text of the legislation.

The text of the law speaks to congressional intent with unusual specificity. Lawmakers wanted to establish a USPHS Ready Reserve Corps "for service in time of national emergency;" that is, to enhance the capability of the USPHS to respond to natural disasters, terrorist incidents, and other public health emergencies "both foreign and domestic." This reflects the growing realization that protection of the public's health is a fundamental component of national security.

Congress intended that USPHS Ready Reserve personnel would be "available on short notice." They would be "available and ready for involuntary calls to active duty during national emergencies and public health crises." They would be available for "backfilling critical positions left vacant" when active-duty USPHS personnel are deployed in response to public health emergencies, both foreign and domestic" and, finally, they would also "be available for service assignments in isolated, hardship, and medically underserved communities." Absent the appropriated funding necessary to meet these legal obligations, the Nation has no public health emergency response capacity.

CONCLUSION

This Association recognizes, of course, that start-up and even continued funding of various provisions of PPACA are a matter of ongoing debate and very much in doubt. But these two provisions—creation of a USPHS Ready Reserve and establishment of a pilot program at USUHS—warrant broad bipartisan support. They are modest, practical, and well thought-through, and they speak to the short-term and long-term national security needs of this country.

I would be pleased to expand on these points or to answer any questions. I can be reached at the COA offices at 301-731-9080, ext. 211.

PREPARED STATEMENT OF THE COUNCIL OF ACADEMIC FAMILY MEDICINE

On behalf of the Council of Academic Family Medicine (CAFM) (Association of Departments of Family Medicine, Association of Family Medicine Residency Directors, North American Primary Care Research Group, and Society of Teachers of Family Medicine), we are pleased to submit testimony on behalf of several programs under the jurisdiction of the Health Resources and Services Administration (HRSA) and the Agency for Healthcare Research and Quality (AHRQ). We thank you for your continued support for programs that encourage the development of primary care physicians to serve our country's healthcare needs. Your fiscal year 2011 committee passed budget was encouraging as a signal of your recognition for the need to invest in these important health professions and workforce programs.

Members of both parties agree there is much that must be done to support primary care production and nourish the development of a high quality, highly effective primary care workforce to serve as a foundation for our healthcare system. Providing strong funding for these programs is essential to the development of a robust workforce needed to provide this foundation.

Primary Care Training and Enhancement

The Primary Care Training and Enhancement Program (Title VII Section 747 of the Public Health Service Act) has a long history of providing indispensable funding for the training of primary care physicians. With each successive reauthorization, Congress has modified the Title VII health professions programs to address relevant workforce needs. The most recent authorization directs the Health Resources and Services Administration (HRSA) to prioritize training in the new competencies relevant to providing care in the patient-centered medical home model. It also calls for the development of infrastructure within primary care departments for the improvement of clinical care and research critical to primary care delivery, as well as inno-

variations in team management of chronic disease, integrated models of care, and transitioning between healthcare settings.

Key advisory bodies such as the Institute of Medicine (IOM) and the Congressional Research Service (CRS) have also called for increased funding. The IOM (December 2008) pointed to the drastic decline in Title VII funding and described these health professions workforce training programs as “an undervalued asset.” The CRS found that reduced funding to the primary care cluster has negatively affected the programs during a time when more primary care is needed (February 2008).

According to the Robert Graham Center, (Title VII’s decline: Shrinking investment in the primary care training pipeline, Oct. 2009), “the number of graduating U.S. allopathic medical students choosing primary care declined steadily over the past decade, and the proportion of minorities within this workforce remains low.” Unfortunately, this decline coincides with a decline in funding of primary care training funding—funding that we know is associated with increased primary care physician production and practice in underserved areas. The report goes on to say that “the Nation needs renewed or enhanced investment in programs like Title VII that support the production of primary care physicians and their placement in underserved areas.”

Title VII has a profound impact on States across the country and is vital to the continued development of a workforce designed to care for the most vulnerable populations and meet the needs of the 21st century. Attached are just a few examples of the impact Title VII has across the country in States like Alabama, Kansas, Ohio, Rhode Island, Tennessee, Texas, and Washington. Included are examples of opportunities lost through the lack of robust funding for the program.

We urge the Congress to appropriate at least \$140 million for the health professions program, Primary Care Training and Enhancement authorized under Title VII, Section 747 of the Public Health Service Act in fiscal year 2012 as requested in the President’s budget.

Rural Physician Training Grants

“Rural Physician Training Grants,” Title VII Section 749B of the Public Health Service Act, were developed to increase the supply of rural physicians by authorizing grants to medical schools which establish or expand rural training. The program would provide grants to produce rural physicians of all specialties. It would help medical schools recruit students most likely to practice medicine in underserved rural communities, provide rural-focused training and experience, and increase the number of medical graduates who practice in underserved rural communities.

According to a July 2007 report of the Robert Graham Center (Medical school expansion: An immediate opportunity to meet rural healthcare needs), data show that although 21 percent of the U.S. population lives in rural areas, only 10 percent of physicians practice there. The Graham Center study describes the educational pipeline to rural medical practice as “long and complex.” There are multiple tactics needed to reverse this situation, and this grant program includes several of them. Strategies to increase the number of physicians practicing in rural areas include “increasing the number of rural-background students in medical school, selecting the “right” students and giving them the “right” content and experiences to train them for rural practice.” This is exactly what this grant program is designed to do.

We request the Committee provide the fully authorized amount of \$4 million in fiscal year 2012 for Title VII Section 749B Rural Physician Training Grants.

Teaching Health Centers

Teaching Health Centers (THC) are community health centers or other similar venues that sponsor residency programs and provide residents with their ambulatory training experiences in the health center. This training in the community, rather than solely at the hospital bedside is one of the hallmarks of family medicine training. However, payment issues have always caused a tension and struggle between the hospital, which currently receives reimbursement for residents it sponsors when they train in the hospital, and programs that require training in non-hospital settings. This program is designed to provide residency programs and community health centers grant funding to plan for a transition in sponsorship, or the establishment of new programs. There are already 11 community-based entities from states across the country that have committed to train 44 primary care residents, demonstrating early success in this program.

We are pleased that THC’s operations are currently funded through a mandatory appropriations trust fund of \$230 million over 5 years, and it is essential that these important centers continue to be funded through this mandatory appropriation. Despite the positive impact that family medicine and other primary care residency

training programs have on those community-based entities that initiate them, a multitude of challenges make it clear that many of these entities would have difficulty doing the same without adequate and predictable financing. Converting this program to discretionary funding also would deter other entities from making the business decisions necessary to expand residency training (e.g., securing commitments from key stakeholders to agree to train new or additional residents, applying for accreditation if not already part of an eligible consortia, and hiring new faculty) since funding over the next few years would be subject to the annual appropriations process.

Teaching Health Center Development Grants

If this program is to be effective, there must be funds for the planning grants to establish newly accredited or expanded primary care residency programs. Teaching Health Center Development Grants are important to help establish these innovative programs.

We recommend the Committee appropriate the full authorized amount for the new Title VII Teaching Health Centers development grants of at least \$10 million for fiscal year 2012.

AHRQ

Research related to the most common acute, chronic, and comorbid conditions that primary care clinicians care for on a daily basis is lacking. Research in these areas is vital because the overall health of a population is directly linked to the strength of its primary healthcare system. AHRQ supports research to improve healthcare quality, reduce costs, advance patient safety, decrease medical errors, and broaden access to essential services. This research is key to helping create a robust primary care system for our Nation—one that delivers higher quality of care and better health while reducing the rising cost of care. Despite this need, little is known about how patients can best decide how and when to seek care, introduce and disseminate new discoveries into real life practice, and how to maximize appropriate care. Ample funding for AHRQ can help researchers address these problems confronting our health system today.

We recommend the Committee fund AHRQ at a level of at least \$405 million for fiscal year 2012

Primary Care Extension Program

The Primary Care Extension Program was modeled after the successful United States Agriculture Extension Service. This program, under Title III of the Public Health Service Act, is designed to support and assist primary care providers with the adoption and incorporation of techniques to improve community health. As the authors of an article describing this concept (JAMA, June 24, 2009) have stated, “To successfully redesign practices requires knowledge transfer, performance feedback, facilitation, and HIT support provided by individuals with whom practices have established relationships over time. The farming community learned these principles a century ago. Primary care practices are like small farms of that era, which were geographically dispersed, poorly resourced for change, and inefficient in adopting new techniques or technology but vital to the Nation’s well-being.”

Congress agreed with the authors that “practicing physicians need something similar to the agricultural extension agent who was so transformative for farming,” and authorized this program at \$120 million for fiscal year 2011 and 2012.

We recommend the Committee fund the Primary Care Extension program at the authorized level of \$120 million for fiscal year 2012.

Title VII Testimonials from the field

Brown University.—“Our Title VII grant is devoted to training students in the care of the underserved. In our first year, we have already recruited two new Community Health Center clinical training sites for our medical students. Our first student at one of the two sites decided, after his family medicine rotation, to change his career path from Urology to Family Medicine.” An additional grant has allowed for the development of a curriculum centered around the Patient Centered Medical Home and Practice transformation and has started transforming family medicine practices in Rhode Island. David Anthony, Director of Medical School Education, and Jeffrey Borkan, MD, PhD, Chair, Department of Family Medicine

East Tennessee State University.—We were able to use a Title VII grant to establish health fairs, including health screening exams, for rural and underserved communities in northeast Tennessee and southwest Virginia. We started small, but now there are 6 health fairs per year, including 2–3 days per event. During the fairs, the average number of visits per site is 180 and we estimate 27,000 visits in 11

years (1999–2010). John Franko MD, Chair and Professor, Department of Family Medicine

The Ohio State University.—With Title VII grants, “We were able to establish a four-track university program—university, academic, urban, and rural, which allowed us to provide a unique training experience involving a diverse population. We have been able to successfully match students in all tracks. We have also been able to provide primary care to the community in settings that were previously physician shortage areas. Finally, we were able to develop training modules for community medicine that address real issues, such as domestic violence, alcohol and substance abuse, teenage pregnancy, obesity, etc.” W. Fred Miser, MD, Associate Professor of Family Medicine

University of Kansas School of Medicine.—The school applied for but did not receive funding for a program designed to help educate volunteer community physician educators. 29 percent of Kansas Medical students go into family medicine but the school has struggled with faculty development education, this is necessary to teach our community physicians the skills necessary to efficiently and effectively teach. Rick Kellerman MD, Professor and Chair, Department of Family and Community Medicine

University of South Alabama.—The Department of Family Medicine applied for but did not receive funding for a program designed to allow us to train residents in a simulated environment to ensure experiences with patients with disability, access and mental health problems. Allen Perkins, MD, MPH, Professor and Chair, Department of Family Medicine

University of Texas Health Science Center at San Antonio.—Title VII grants are helping the program transition to be core transitional laboratories for the NIH’s Clinical and Translational Science Awards (CTSA) efforts and have helped in getting support for a new a Practice Based Research Network Resource Center for community engagement. Carlos Roberto Jaen, MD PhD FAFAP, Professor of Epidemiology and Health Statistics

WWAMI (a partnership between the University of Washington School of Medicine and the States of Wyoming, Alaska, Montana, and Idaho).—Title VII grants have helped fund over 30 faculty positions across the States of Washington, Wyoming, Alaska, Montana, and Idaho. These grants have helped fund the development of areas of scholarship for residency programs in Montana, assisted in the training of fellows that became Residency Directors at other programs, and funded faculty development programs delivered with televideo to rural areas in Wyoming. Ardis Davis MSW, University of Washington Department of Family Medicine, Teaching Associate

Thomas Jefferson Medical School.—Title VII grants have allowed us to expand our successful rural Physician Shortage Area and Urban Underserved Programs, teach all of our students about the Patient Centered Medical Home in all 4 years of medical school, and train over 1,400 students, residents, and faculty in community medicine and population health. We have also expanded the infrastructure and rigor of our research fellowship, doubling the publication outcomes of our research fellows over the past 2 years. Howard Rabinowitz, Department of Family and Community Medicine

PREPARED STATEMENT OF THE COUNCIL ON SOCIAL WORK EDUCATION

On behalf of the Council on Social Work Education (CSWE), I am pleased to offer this written testimony to the Senate Appropriations Subcommittee on Labor, Health and Human Services, Education, and Related Agencies for inclusion in the official Committee record. I will focus my testimony on the importance of fostering a skilled, sustainable, and diverse social work workforce to meet the healthcare needs of the Nation through professional education, training and financial support programs at the Department of Health and Human Services (HHS) and the Department of Education (ED).

CSWE is a nonprofit national association representing more than 3,000 individual members as well as 650 master’s and baccalaureate programs of professional social work education. Founded in 1952, this partnership of educational and professional institutions, social welfare agencies, and private citizens is recognized by the Council for Higher Education Accreditation (CHEA) as the single accrediting agency for social work education in the United States. Social work education focuses students on leadership and direct practice roles helping individuals, families, groups, and communities by creating new opportunities that empower people to be productive, contributing members of their communities.

Social work is rooted in a tradition of social justice, with a central mission of eliminating inequities by helping vulnerable populations navigate societal and personal challenges. Social workers are embedded in a variety of settings, such as schools, hospitals, Veteran health facilities, rehabilitation centers, social service agencies, child welfare organizations, assisted living centers, nursing homes, and faith-based organizations, which allows us to reach diverse segments of the population and play a significant role in the lives of Americans from all walks of life. For example, we provide psychosocial support for individuals and families to help them cope with disease, such as Alzheimer's disease and cancer; we assist families who struggle with homelessness and un- or underemployment; we work with families dealing with domestic violence, including child and spousal abuse; and we work with children in school or afterschool settings to ensure that they meet their full academic potential and to help them cope with issues they may be experiencing in their home lives. As you can see, social workers have an important role to play in all aspects of daily life.

Unfortunately, recruitment and retention in social work continues to be a serious challenge that threatens the workforce's ability to meet societal needs. The U.S. Bureau of Labor Statistics estimates that employment for social workers is expected to grow faster than the average for all occupations through 2018, particularly for social workers specializing in the aging population and working in rural areas. In addition, the need for mental health and substance abuse social workers is expected to grow by almost 20 percent over the 2008–2018 decade.¹

Recruitment into the social work profession faces many obstacles, the most prevalent being low wages coupled with high educational debt. For example, the median annual wage for child, family, and school social workers in May 2008 was \$39,530, while the wage for mental health and substance abuse social workers was \$37,210. While a bachelor's degree (BSW) is necessary for most entry-level positions, a master's degree (MSW) is the terminal degree for social work practice, which significantly contributes to the debt load of social work graduates entering careers with low starting wages. According to the 2007–2008 National Postsecondary Student Aid Study conducted by the National Center for Education Statistics at ED, 72 percent of students graduating from MSW programs incurred debt to earn their graduate degree. The average debt was approximately \$35,500. The percentage of MSW students borrowing money is 17 percent higher than the average for all master's degrees and the amount borrowed is approximately \$5,000 higher than the average for all master's degrees. These difficult realities have made recruitment and retention of social workers an ongoing challenge.

CSWE understands and appreciates the tough funding decisions Congress is faced with this year. However, we urge you to consider the needs of our frontline workforce if we are to see real progress in meeting the healthcare and societal demands of the Nation. The below recommendations for fiscal year 2012 would help to ensure that we are fostering a sustainable, skilled, and diverse workforce that will be able to keep up with the increasing demand for social work services.

HEALTH RESOURCES AND SERVICES ADMINISTRATION (HRSA) TITLE VII AND TITLE VIII HEALTH PROFESSIONS PROGRAMS

CSWE urges the Subcommittee to provide \$762.5 million for the Title VII and Title VIII health professions programs at HRSA in fiscal year 2012. HRSA's Title VII and Title VIII health professions programs represent the only Federal programs designed to train healthcare providers in an interdisciplinary way to meet the healthcare needs of all Americans, including the underserved and those with special needs. These programs also serve to increase minority representation in the healthcare workforce through targeted programs that improve the quality, diversity, and geographic distribution of the health professions workforce. The Title VII and Title VIII programs provide loans, loan guarantees and scholarships to students, and grants to institutions of higher education and nonprofit organizations to help build and maintain a robust healthcare workforce. Social workers and social work students are eligible for Title VII funding.

The Title VII and Title VIII programs were reauthorized in 2010, which helped to improve the efficiency of the programs as well as enhance efforts to recruit and retain health professionals in underserved communities. Allow me to highlight a few of the programs that are of critical importance to the training of social workers.

—*Mental and Behavioral Health Education and Training.*—Recognizing the severe shortages of mental and behavioral health providers within the healthcare

¹ U.S. Bureau of Labor Statistics. 2009. *Occupational Outlook Handbook, 2010–11 Edition: Social Workers*, <http://data.bls.gov/cgi-bin/print.pl/oco/ocos060.htm>. Retrieved April 13, 2011.

workforce, a new Title VII program was authorized in the Patient Protection and Affordable Care Act (Public Law 111–148). This program—Mental and Behavioral Health Education and Training Grants—would provide grants to institutions of higher education (schools of social work and other mental health professions) for faculty and student recruitment and professional education and training. The President’s budget request includes \$17.9 million for these grants in fiscal year 2012. This funding would allow for approximately 10 grants in graduate social work education, 17 grants in graduate psychology education, 12 grants for professional child and adolescent mental health education, and 6 grants for paraprofessional child and adolescent mental health. This is the only program in the Federal Government that is explicitly focused on recruitment and retention of social workers and other mental and behavioral health professionals. CSWE strongly urges the Subcommittee to provide \$17.9 million for the Title VII Mental and Behavioral Health Education and Training Grants in fiscal year 2012.

—*Geriatrics Health Professions Training.*—Within the overall request for HRSA’s Title VII and Title VIII programs, CSWE urges the Subcommittee to appropriate \$46.5 million for Geriatrics Health Professions Programs. This includes the Geriatric Academic Career Incentive Awards (GACA), Geriatric Education Centers (GEC), and Geriatric Career Incentive Awards. As mentioned earlier, the reauthorization that occurred last year made enhancement to the Title VII and Title VIII programs. Specifically, the reauthorization enhanced the geriatrics programs to allow additional health professions—such as social workers and other mental healthcare providers—to participate. Rapid job growth is anticipated for gerontological social workers. In fact, the demand for geriatric social workers is expected to increase by 45 percent by 2015, faster than the average of all other occupations². Additional funding for these programs is needed to ensure that the geriatric workforce is adequately equipped to deal with the aging population, which is only expected to grow to breaking-point levels within the next several years.

SUBSTANCE ABUSE AND MENTAL HEALTH SERVICES ADMINISTRATION (SAMHSA) MINORITY FELLOWSHIP PROGRAM

The goal of the SAMHSA Minority Fellowship Program (MFP) is to achieve greater numbers of minority doctoral students preparing for leadership roles in the mental health and substance abuse fields. According to SAMHSA, minorities make up approximately one-fourth of the population, but only about 10 percent of mental health providers are ethnic minorities. CSWE is a grantee of this critical program and administers funds to exceptional minority social work students. For fiscal year 2012, CSWE urges the Subcommittee to appropriate \$7.5 million to the SAMHSA Minority Fellowship Program. This would include \$6.882 million for the Center for Mental Health Services, where the majority of MFP funds are administered; \$71,000 for the Center for Substance Abuse Prevention; and \$547,000 for the Center for Substance Abuse Treatment.

The program has helped support doctoral-level professional education for over 1,000 ethnic minority social workers, psychiatrists, psychologists, psychiatric nurses, and family and marriage therapists since its inception. Still, the program continues to struggle to keep up with the demands that are plaguing our health professions. Severe shortages of mental health professionals often arise in underserved areas due to the difficulty of recruitment and retention in the public sector. Nowhere are these shortages more prevalent than in Indian Country, where mental illness and substance abuse go largely untreated and incidences of suicide continue to increase. Studies have shown that ethnic minority mental health professionals practice in underserved areas at a higher rate than non-minorities. Furthermore, a direct positive relationship exists between the numbers of ethnic minority mental health professionals and the utilization of needed services by ethnic minorities.

The \$7.5 million request would be used to substantially increase access to professional education and training for additional minority mental health and substance abuse professionals, in turn helping to ensure that underserved minority populations receive the mental health and substance abuse services they so desperately need. President Obama’s fiscal year 2012 budget request includes flat funding for the MFP at about \$4.9 million. Funding the MFP at \$7.5 million would directly encourage more social workers of minority backgrounds to pursue doctoral degrees in

²Hooyman, N., and Unützer, J. 2011. “A Perilous Arc of Supply and Demand: How Can America Meet the Multiplying Mental Health Care Needs of an Aging Population?” *Generations* 34 (4): 36–42.

mental health and substance abuse and will turnout more minority mental health professionals equipped to provide culturally competent, accessible mental health and substance abuse services to diverse populations.

DEPARTMENT OF EDUCATION STUDENT AID PROGRAMS

CSWE supports full funding to keep the maximum Pell Grant at \$5,550 in fiscal year 2012. While Congress is understandably focused on identifying a solution that will place the Pell Grant program on solid ground in regards to its fiscal future, we urge you to remember that these grants help to ensure that all students, regardless of their economic situation, can achieve higher education. Moreover, as described above with regard to the SAMHSA Minority Fellowship Program, one goal of social work education is recruiting students from diverse backgrounds (which includes racial, economic, religious, and other forms of diversity) with the hope that they will return to serve diverse communities once they have completed their education. In many cases, this includes encouraging social workers to return to their own communities and apply the skills they have acquired through their social work education to individuals, groups, or families in need. Without support such as Pell Grants, many low-income individuals would not be able to access higher education, and in turn, would not acquire skills needed to best serve in the communities that would most benefit from their service.

The Graduate Assistance in Areas of National Need (GAANN) program provides graduate traineeships in critical fields of study. Currently, social work is not defined as an area of national need for this program; however it was recognized by Congress as an area of national need in the Higher Education Opportunity Act of 2008. We are hopeful that ED will recognize the importance of including social work in the GAANN program in future years. Inclusion of social work would help to significantly enhance graduate education in social work, which is critically needed in the country's efforts to foster a sustainable health professions workforce. CSWE urges the Subcommittee to provide \$31 million for the GAANN Program. However, if social work was to be added by the Department as a new area of national need, additional resources would need to be provided so as not to take funding away from the already determined areas of national need.

Thank you for the opportunity to express these views. Please do not hesitate to call on the Council on Social Work Education should you have any questions or require additional information.

PREPARED STATEMENT OF THE CROHN'S AND COLITIS FOUNDATION OF AMERICA

Mr. Chairman and members of the Subcommittee, thank you for the opportunity to submit testimony on behalf of the 1.4 million Americans living with Crohn's disease and ulcerative colitis. My name is Gary Sinderbrand and I have the privilege of serving as the Chairman of the National Board of Trustees for the Crohn's and Colitis Foundation of America. CCFA is the Nation's oldest and largest voluntary organization dedicated to finding a cure for Crohn's disease and ulcerative colitis—collectively known as inflammatory bowel diseases.

Let me express at the outset how appreciative we are for the leadership this Subcommittee has provided in advancing funding for the National Institutes of Health.

Mr. Chairman, Crohn's disease and ulcerative colitis are devastating inflammatory disorders of the digestive tract that cause severe abdominal pain, fever and intestinal bleeding. Complications include arthritis, osteoporosis, anemia, liver disease and colorectal cancer. We do not know their cause, and there is no medical cure. They represent the major cause of morbidity from digestive diseases and forever alter the lives of the people they afflict—particularly children. I know, because I am the father of a child living with Crohn's disease.

Seven years ago, during my daughter, Alexandra's sophomore year in college, she was taken to the ER for what was initially thought to be acute appendicitis. After a series of tests, my wife and I received a call from the attending GI who stated coldly: Your daughter has Crohn's disease, there is no cure and she will be on medication the rest of her life. The news froze us in our tracks. How could our vibrant, beautiful little girl be stricken with a disease that was incurable and has ruined the lives of countless thousands of people?

Over the next several months, Alexandra fluctuated between good days and bad. Bad days would bring on debilitating flares which would rack her body with pain and fever as her system sought equilibrium. Our hearts were filled with sorrow as we realized how we were so incapable of protecting our child.

Her doctor was trying increasingly aggressive therapies to bring the flares under control.

Asacol, Steroids, Mercaptopurine, Methotrexate and finally Remicade. Each treatment came with its own set of side effects and risks. Every time A would call from school, my heart would jump before I picked up the call in fear of hearing that my child was in pain as the flares had returned. Ironically, the worst call came from one of her friends to report that A was back in the ER and being evaluated by a GI surgeon to determine if an emergency procedure was needed to clear an intestinal blockage that was caused by the disease. Several hours later, a brilliant surgeon at the University of Chicago, removed over a foot of diseased tissue from her intestine. The surgery saved her life, but did not cure her. We continue to live every day knowing that the disease could flare at any time with devastating consequences.

Mr. Chairman, I will focus the remainder of my testimony on our appropriations recommendations for fiscal year 2012.

RECOMMENDATIONS FOR FISCAL YEAR 2012

Centers For Disease Control And Prevention

Inflammatory Bowel Disease Epidemiology Program

As I mentioned earlier, CCFA estimates that 1.4 million people in the United States suffer from IBD, but there could be many more. We do not know the exact number due to the complexity of these diseases and the difficulty in identifying them. The Centers for Disease Control and Prevention's Inflammatory Bowel Disease Program is helping answer this and many other important questions related to these challenging conditions. This program is the only one of its kind and its accomplishments have been applauded by the CDC.

CCFA has been a proud partner with CDC in conducting the research funded under the epidemiology program. For the first 2 years of the project the Foundation worked collaboratively with Kaiser Permanente in California to better understand the incidence and prevalence of IBD, the natural history of the disease, and why patients respond differently to the same therapy. This research has resulted in 11 publications to date and another 11 papers to be submitted to high-quality peer-reviewed journals. Topics include but are not limited to the following:

- Incidence and Prevalence of IBD
- Patterns of Care and Outcomes in IBD
- Qualitative study of provider opinions
- Utilization of biologics (Infliximab)
- Disparities in Mortality
- Myelosuppression during Thiopurine Therapy for Inflammatory Bowel Disease: Implications for Monitoring Recommendations
- Severity and Flare Algorithms
- Disparities in Surveillance for Colorectal Cancer
- Pediatric Epidemiology

In 2007, our focus shifted to the establishment of the "Ocean State Crohn's & Colitis Area Registry" or OSCCAR. Under the leadership of Dr. Bruce Sands, this study is being conducted jointly by investigators at the Massachusetts General Hospital and Rhode Island Hospital/Brown University. The State of Rhode Island is an excellent location to conduct a population-based IBD study because; (1) it is a small State geographically; (2) it has a diverse ethnic and socioeconomic population that does not tend to migrate out of State; and (3) a small number of gastroenterologists treat essentially all IBD patients within the State. Since 2007, Dr. Sands has been able to recruit virtually all GI physicians in Rhode Island to refer patients into the study. To date, almost 310 patients have been recruited, 89 of whom are pediatric patients. All of this progress will be lost if the program is eliminated in 2012.

The goals of the OSCCAR study moving forward are to: (1) describe the age and sex adjusted incidence rate of Crohn's disease and ulcerative colitis; (2) describe variations in presenting symptoms among children, men and women with newly diagnosed disease; (3) identify factors that predict resistance to steroids, including clinical characteristics and blood test markers that could be useful to treating physicians; (4) identify predictors of the need for surgery; and (5) describe factors that predict either impaired quality of life or a benign course of disease. Mr. Chairman, to ensure that this important epidemiological work moves forward in fiscal year 2012, CCFA recommends an appropriation of \$680,000 (fiscal year 2010 level).

Pediatric Inflammatory Bowel Disease Patient Registry

Mr. Chairman, the unique challenges faced by children and adolescents battling IBD are of particular concern to CCFA. In recent years we have seen an increased prevalence of IBD among children, particularly those diagnosed at a very early age. To combat this alarming trend CCFA, in partnership with the North American Soci-

ety for Pediatric Gastroenterology, Hepatology and Nutrition, has instituted an aggressive pediatric research campaign focused on the following areas:

- Growth/Bone Development.*—How does inflammation cause growth failure and bone disease in children with IBD?
- Genetics.*—How can we identify early onset Crohn's disease and ulcerative colitis?
- Quality Improvement.*—Given the wide variation in care provided to children with IBD, how can we standardize treatment and improve patients' growth and well-being?
- Immune Response.*—What alterations in the childhood immune system put young people at risk for IBD, how does the immune system change with treatment for IBD?
- Psychosocial Functioning.*—How does diagnosis and treatment for IBD impact depression and anxiety among young people? What approaches work best to improve mood, coping, family function, and quality of life.

The establishment of a national registry of pediatric IBD patients is central to our ability to answer these important research questions. Empowering investigators with HIPPA compliant information on young patients from across the Nation will jump-start our effort to expand epidemiologic, basic and clinical research on our pediatric population. We encourage the Subcommittee to support our efforts to establish a Pediatric IBD Patient Registry with the CDC in fiscal year 2012.

National Institutes of Health

Throughout its 40 year history, CCFA has forged remarkably successful research partnerships with the NIH, particularly the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK), which sponsors the majority of IBD research, and the National Institute of Allergy and Infectious Diseases (NIAID). CCFA provides crucial "seed-funding" to researchers, helping investigators gather preliminary findings, which in turn enables them to pursue advanced IBD research projects through the NIH. This approach led to the identification of the first gene associated with Crohn's—a landmark breakthrough in understanding this disease.

Mr. Chairman, NIDDK-sponsored research on IBD has been a remarkable success story. In 2008, a consortium of researchers from the United States, Canada, and Europe identified 21 new genes for Crohn's disease. This discovery, funded in part by the NIDDK, brings the total number of known genes associated with Crohn's disease to more than 30 and provides new avenues for the development of promising treatments. We are grateful for the leadership of Dr. Stephen James, Director of NIDDK's Division of Digestive Diseases and Nutrition, for aggressively pursuing this and other promising areas of research.

CCFA's scientific leaders, with significant involvement from NIDDK, have developed an ambitious research agenda entitled "Challenges in Inflammatory Bowel Diseases." In addition, CCFA-affiliated investigators played a leading role in developing the recommendations on IBD in the new NIH National Commission on Digestive Diseases strategic plan. We look forward to working with the NIDDK to advance the cutting-edge science called for in these two roadmaps.

For fiscal year 2012, CCFA joins with other voluntary patient and medical organizations in recommending an appropriation of \$35 billion for the NIH. Once again Mr. Chairman, thank you very much for the opportunity to submit our views for your consideration.

PREPARED STATEMENT OF THE CYSTIC FIBROSIS FOUNDATION

On behalf of the Cystic Fibrosis Foundation and the 30,000 Americans with cystic fibrosis (CF), we are pleased to submit the following testimony with our requests for fiscal year 2012 Labor, Health and Human Services, and Education Appropriations.

ABOUT CYSTIC FIBROSIS

Cystic fibrosis is a life-threatening genetic disease for which there is no cure. People with CF have two copies of a defective gene, known as CFTR, which causes the body to produce abnormally thick, sticky mucus that clogs the lungs and results in fatal lung infections. The thick mucus in those with CF also obstructs the pancreas, making it difficult for patients to absorb nutrients from food.

Since its founding, the CF Foundation has maintained its focus on promoting research and improving treatments for CF. More than 30 drugs are now in development to treat CF; some treat the basic defect of the disease, while others target its symptoms. Through the research leadership of the Cystic Fibrosis Foundation, peo-

ple with CF are living into their 30s, 40s and beyond. This improvement in the life expectancy for those with CF can be attributed to research advances and to the teams of CF caregivers who offer specialized care. Although life expectancy has improved dramatically, we continue to lose young lives to this disease.

The promise for people with CF lies in research. In the past 6 years, the Cystic Fibrosis Foundation has invested over \$1 billion in its medical programs of drug discovery, drug development, research, and care focused on life-sustaining treatments and a cure for CF. A greater investment is necessary, however, to accelerate the pace of discovery and development of CF therapies.

SUSTAINING THE FEDERAL INVESTMENT IN BIOMEDICAL RESEARCH

This Committee and Congress are to be commended for their support for biomedical research through the years. It is vital that we continue to sufficiently fund the NIH, so that it can capitalize on scientific advances and maintain the momentum generated by the doubling of funds and the infusion from the American Recovery and Reinvestment Act (ARRA). These increases in funding brought a new era in drug discovery that has benefited all Americans.

Cutting discretionary health spending by 13.5 percent, as has been proposed, would halt this progress. Deep cuts would have a detrimental effect on the fight against many of our most serious diseases, stifle scientific opportunities, and result in high-wage job loss in all 50 States. In 2007, NIH grants and contracts created and supported more than 350,000 jobs across the United States, an important contribution to the American economy.

We urge this Committee and Congress to maintain robust investment in biomedical research at the NIH so it can fund critical research today that will provide the care and cures of tomorrow.

STRENGTHENING CLINICAL RESEARCH AND DRUG DEVELOPMENT

The Cystic Fibrosis Foundation has been recognized for its unique research approach, which encompasses everything from basic research through Phase 4 post-marketing monitoring of drug safety, and has created the infrastructure required to accelerate the development of new CF therapies. As a result, we now have a pipeline of more than 30 potential therapies that are being examined to treat people with CF.

One such treatment is VX-770, a drug being developed by Vertex Pharmaceuticals that was discovered in collaboration with CFF. This promising therapy targets the physiological defect that causes CF in patients with a particular type of genetic mutation, as opposed to only addressing symptoms of the disease. In late February 2011 we learned that Phase 3 clinical trial data of VX-770 showed profound improvements in lung function and other health measures in CF patients, and a New Drug Application is expected to be submitted to the FDA for review later this year. This new treatment is a direct result of the Foundation's innovative research agenda, advancing from bench to bedside through the Foundation's research program which speeds the creation of new CF therapies.

The Foundation is a leader in creating a clinical trials network to achieve greater efficiency in clinical investigation. Because the CF population is small, a higher proportion of people with the disease must partake in clinical trials than in most other diseases. This unique challenge prompted the Foundation to streamline our clinical trials processes. As a result, research conducted by the Foundation is more efficient than ever before and we are a model for other disease groups.

While the CF Foundation has made great progress in creating a more efficient drug development process for cystic fibrosis, still more needs to be done for other rare diseases, many of which have no treatments available. The Federal Government has the opportunity to make a real difference in this regard, and we are hopeful that the Committee will direct the national health agencies to encourage all investigators and institutions receiving Federal funding to advance novel methodologies and mechanisms for translating basic research into therapies that can benefit patients.

Advancing Translational Science

The CF Foundation strongly urges this Committee and Congress to support funding for NIH's proposed National Center for Advancing Translational Sciences (NCATS), which will house the Institutes' existing translational science programs while establishing and providing a more focused, integrated, and systematic approach for linking basic discovery to therapeutic development.

The existing programs to be housed under NCATS are integral to translating basic science into treatments and will benefit from funding for the new center.

These programs include Clinical and Translational Science Awards (CTSA), discussed in further detail below, and the newly authorized Cures Acceleration Network (CAN), both designed to transform the way in which clinical and translational research is conducted and funded. The Therapeutics for Rare and Neglected Diseases (TRND) program will also be housed in the new center. NIH Director Collins has specifically cited the Cystic Fibrosis Foundation's Therapeutics Development Network (TDN), which plays a pivotal role in accelerating the development of new treatments for cystic fibrosis patients, as an exemplar for TRND's innovative therapeutics development model.

The Foundation's investment in pharmaceutical and biotech companies can also serve as a model for the new center's overall mission. NCATS, like CFF, will promote public-private partnerships and convene cross-sector collaborations between industry, government, academia, and others to advance drug development, as well as provide services and resources for high throughput screening, assay development, and preclinical modeling. Prioritizing these initiatives through a standalone center at NIH has the potential to greatly accelerate the development of drugs for diseases that have historically received little pharmaceutical industry attention. In addition, integrating translational science programs from throughout NIH into one center will help bring greater efficiency to the Institutes' pursuit of this important research. Once again, we applaud NIH Director Collins for spearheading NCATS and look forward to working with him as this new initiative is implemented.

Clinical and Translational Science Awards (CTSA)

The CTSA program, soon to be housed in NCATS, encourages novel approaches to clinical and translational research, enhances the utilization of informatics, and strengthens the training of young investigators. Key to the success of CSAs is the parallel maintenance of infrastructure support for Clinical Research Centers (CRC). Without a mechanism to offset clinical research costs, young investigators or Principle Investigators (PIs) studying rare diseases for which there is limited funding will not be able to continue to conduct clinical research. It is important that all NIH institutes recognize that there is a significant cost associated with the conduct of well designed and safe clinical trials, and not all of these costs can be borne by the CSAs. Congress should direct the NIH to cover costs that used to be borne by the General Clinical Research Centers (GCRCs) through individual research grants.

Support should also be directed toward the continuation and expansion of research networks, such as NIH's pediatric liver disease consortium at the National Institute of Diabetes, Digestive, and Kidney Diseases (NIDDK). This successful collaboration is helping researchers discover treatments not only for CF liver disease but for other diseases that affect thousands of children each year.

SUPPORTING DRUG DISCOVERY

The Cystic Fibrosis Foundation's clinical research is fueled by a vigorous drug discovery effort comprised of early stage translational research into successful treatments for this disease. Several research projects at the NIH will expand our knowledge about the disease, and could eventually be the key to controlling or curing cystic fibrosis.

Opportunities in Animal Models

The Cystic Fibrosis Foundation is encouraged by the NIH's investment in a research program at the University of Iowa to study the effects of CF in a pig model. The program, funded through research awards from both the National Heart, Lung, and Blood Institute (NHLBI) and the Cystic Fibrosis Foundation, bears great promise to help make significant developments in the search for a cure. While a company has been established to produce the animals, the infrastructure and extensive animal husbandry required to keep the animals alive and conduct research on them is available at few academic institutions. Such barriers have greatly limited widespread adoption of these valuable research tools. We urge additional funding to create a common facility that would enable researchers from multiple institutions to conduct research with these models.

Understanding CFTR Folding and Trafficking

The data that emerged from the VX-770 Phase 2 and 3 clinical trials, discussed above, is proof that the way in which this drug targets the physiological defect that causes CF, called CFTR protein function modulation, is a viable therapeutic approach. However, this exciting data was obtained from patients with a specific CF mutation which affects only approximately 4 percent of CF patients. More research is needed to understand other genetic mutations, the most common of which is called F508del. F508del causes multiple negative effects, including misfolding and

poor activation properties of the CFTR protein. We encourage the Committee to increase investment in genetic research that can help scientists to better understand the F508del mutation. This will facilitate CF drug discovery and has the potential to benefit not just those with cystic fibrosis, but also those with other protein misfolding diseases.

Personalized Medicine

Strong Federal and private investment in research is bringing personalized medicine into the forefront. As we gain a deeper understanding of many diseases and their accompanying genetic profiles, we understand the great challenge of personalizing therapies. While exciting and promising for patients, it is also expensive, complex, and scientifically challenging. For instance, CF doctors are facing difficulties in delivering appropriate care to CF patients, as insurance providers will not cover certain combinations of medicines that clinicians have found are effective for cystic fibrosis in particular when there is no formal clinical data to support it. This puts patients in a difficult position, as these clinical trials are expensive and unlikely to be performed by pharmaceutical companies, especially for treatment of a small, targeted population. As such we urge the Committee to provide sustained Federal investment in personalized medicine, to help move this burgeoning field forward and advance exciting scientific discoveries.

SUPPORTING GREATER ACCESS TO QUALITY HEALTH CARE

We are making remarkable strides in our fight against cystic fibrosis, but people who live with it face greater obstacles each year, as high medical costs can prevent them from accessing appropriate medical care. Healthcare for a CF patient costs \$64,000 per year on average, 15 times more than that of the average person. Because of high costs, nearly a quarter of CF patients delay getting medical care or skip treatments their providers recommend to enhance and lengthen their life.

The Foundation sees some promise in a number of provisions in the new healthcare reform law that increase access to health insurance coverage for those with rare and chronic diseases, a critical tool in decreasing out of pocket costs for patients. These provisions include those allowing children to remain on their parents' insurance until they are 26; prohibiting insurance companies from denying or rescinding coverage based on a pre-existing condition; banning annual and lifetime caps on coverage; and the expansion of Medicaid eligibility.

The new law is not perfect, however, and we are concerned that while the provisions listed above will ensure continuity of coverage and greater access to care for those with CF and other chronic diseases, more must be done to reduce the financial burden so many families face in affording their care, especially in these challenging economic times.

While we urge Congress to explore new options to help make care more affordable and reduce shifting costs to patients, we ask that provisions that have the potential to provide desperately needed relief to people with cystic fibrosis be retained, and that they are sufficiently funded so that those with rare and chronic diseases can access the care they need.

In addition, the Foundation wishes to applaud the formation of the Patient Centered Outcomes Research Institute (PCORI) and urges the Committee to support this important entity. PCORI, a private non-profit institute created by the Patient Protection and Affordable Care Act, will support and direct research that gives patients, doctors, and others the information they need make informed decisions about the most effective and appropriate methods for preventing and treating health conditions. The CF Foundation has had great success in improving quality of care for cystic fibrosis patients through the development and administration of a comprehensive patient registry and the collection of comprehensive data on outcomes and practice patterns for use in comparative effectiveness research, and we are confident that dedicating a national institute to such pursuits will improve care for all Americans.

The Cystic Fibrosis Foundation has devoted our own resources to developing treatments through drug discovery, clinical development, and clinical care. Several of the drugs in our pipeline show remarkable promise in clinical trials and we are increasingly hopeful that these discoveries will bring us even closer to a cure. However, sufficient investment in basic science, translational science, clinical research, and drug development programs at NIH is needed to continue these successes not only for CF but for all rare diseases. Additionally, funding for programs that promote access and quality of care will help achieve a greater quality of life for those living with chronic diseases like cystic fibrosis.

We urge the Committee to consider these factors as you craft the fiscal year 2012 Labor, Health and Human Services, and Education Appropriations legislation, and

stand ready to work with NIH and Congressional leaders on the challenging issues ahead. Thank you for your consideration.

PREPARED STATEMENT OF THE DIGESTIVE DISEASE NATIONAL COALITION

Summary of Fiscal Year 2012 Recommendations

\$35 billion for the National Institutes of Health (NIH) at an increase of 12 percent over fiscal year 2011. Increase funding for the National Cancer Institute (NCI), the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) and the National Institute of Allergy and Infectious Diseases (NIAID) by 12 percent.

Continue focus on digestive disease research and education at NIH, including the areas of inflammatory bowel disease (IBD), hepatitis and other liver diseases, irritable bowel syndrome (IBS), colorectal cancer, endoscopic research, pancreatic cancer, and celiac disease.

\$50 million for the Centers for Disease Control and Prevention's (CDC) hepatitis prevention and control activities.

\$50 million for the Center for Disease Control and Prevention's (CDC) colorectal cancerscreening and prevention program.

Chairman Rehberg, thank you for the opportunity to again submit testimony to the Subcommittee. Founded in 1978, the Digestive Disease National Coalition (DDNC) is a voluntary health organization comprised of 29 professional societies and patient organizations concerned with the many diseases of the digestive tract. The DDNC promotes a strong Federal investment in digestive disease research, patient care, disease prevention, and public awareness. The DDNC is a broad coalition of groups representing disorders such as Inflammatory Bowel Disease (IBD), Hepatitis and other liver diseases, Irritable Bowel Syndrome (IBS), Pancreatic Cancer, Ulcers, Pediatric and Adult Gastroesophageal Reflux Disease, Colorectal Cancer, and Celiac Disease.

Mr. Chairman, the social and economic impact of digestive disease is enormous and difficult to grasp. Digestive disorders afflict approximately 65 million Americans. This results in 50 million visits to physicians, over 10 million hospitalizations, collectively 230 million days of restricted activity. The total cost associated with digestive diseases has been conservatively estimated at \$60 billion a year.

The DDNC would like to thank the Subcommittee for its past support of digestive disease research and prevention programs at the National Institutes of Health (NIH) and the Centers for Disease Control and Prevention (CDC).

Specifically the DDNC recommends: \$2.16 billion for the National Institute of Diabetes and Digestive and Kidney Disease (NIDDK); and \$35 billion for the NIH.

We at the DDNC respectfully request that any increase for NIH does not come at the expense of other Public Health Service agencies. With the competing and the challenging budgetary constraints the Subcommittee currently operates under, the DDNC would like to highlight the research being accomplished by NIDDK which warrants the increase for NIH.

Inflammatory Bowel Disease

In the United States today about 1 million people suffer from Crohn's disease and ulcerative colitis, collectively known as Inflammatory Bowel Disease (IBD). These are serious diseases that affect the gastrointestinal tract causing bleeding, diarrhea, abdominal pain, and fever. Complications arising from IBD can include anemia, ulcers of the skin, eye disease, colon cancer, liver disease, arthritis, and osteoporosis. The cause of IBD is still unknown, but research has led to great breakthroughs in therapy.

In recent years researchers have made significant progress in the fight against IBD. The DDNC encourages the subcommittee to continue its support of IBD research at NIDDK and NIAID at a level commensurate with the overall increase for each institute. The DDNC would like to applaud the NIDDK for its strong commitment to IBD research through the Inflammatory Bowel Disease Genetics Research Consortium. The DDNC urges the Consortium to continue its work in IBD research. Therefore the DDNC and its member organization the Crohn's and Colitis Foundation of America encourage the CDC to continue to support a nationwide IBD surveillance and epidemiological program in fiscal year 2012.

Viral Hepatitis: A Looming Threat to Health

The DDNC applauds all the work NIH and CDC have accomplished over the past year in the areas of hepatitis and liver disease. The DDNC urges that funding be focused on expanding the capability of State health departments, particularly to enhance resources available to the hepatitis State coordinators. The DDNC also urges

that CDC increase the number of cooperative agreements with coalition partners to develop and distribute health education, communication, and training materials about prevention, diagnosis and medical management for viral hepatitis.

The DDNC supports \$50 million for the CDC's Hepatitis Prevention and Control activities. The hepatitis division at CDC supports the hepatitis C prevention strategy and other cooperative nationwide activities aimed at prevention and awareness of hepatitis A, B, and C. The DDNC also urges the CDC's leadership and support for the National Viral Hepatitis Roundtable to establish a comprehensive approach among all stakeholders for viral hepatitis prevention, education, strategic coordination, and advocacy.

Colorectal Cancer Prevention

Colorectal cancer is the third most commonly diagnosed cancer for both men and woman in the United States and the second leading cause of cancer-related deaths. Colorectal cancer affects men and women equally.

The DDNC recommends a funding level of \$50 million for the CDC's Colorectal Cancer Screening and Prevention Program. This important program supports enhanced colorectal screening and public awareness activities throughout the United States. The DDNC also supports the continued development of the CDC-supported National Colorectal Cancer Roundtable, which provides a forum among organizations concerned with colorectal cancer to develop and implement consistent prevention, screening, and awareness strategies.

Pancreatic Cancer

In 2006, an estimated 33,730 people in the United States will be found to have pancreatic cancer and approximately 32,300 will die from the disease. Pancreatic cancer is the fifth leading cause of cancer death in men and women. Only 1 out of 4 patients will live 1 year after the cancer is found and only 1 out of 25 will survive 5 or more years.

The National Cancer Institute (NCI) has established a Pancreatic Cancer Progress Review Group charged with developing a detailed research agenda for the disease. The DDNC encourages the Subcommittee to provide an increase for pancreatic cancer research at a level commensurate with the overall percentage increase for NCI and NIDDK.

Irritable Bowel Syndrome (IBS)

IBS is a disorder that affects an estimated 35 million Americans. The medical community has been slow in recognizing IBS as a legitimate disease and the burden of illness associated with it. Patients often see several doctors before they are given an accurate diagnosis. Once a diagnosis of IBS is made, medical treatment is limited because the medical community still does not understand the pathophysiology of the underlying conditions.

Living with IBS is a challenge, patients face a life of learning to manage a chronic illness that is accompanied by pain and unrelenting gastrointestinal symptoms. Trying to learn how to manage the symptoms is not easy. There is a loss of spontaneity when symptoms may intrude at any time. IBS is an unpredictable disease. A patient can wake up in the morning feeling fine and within a short time encounter abdominal cramping to the point of being doubled over in pain and unable to function.

Mr. Chairman, much more can still be done to address the needs of the nearly 35 million Americans suffering from irritable bowel syndrome and other functional gastrointestinal disorders. The DDNC recommends that NIDDK increase its research portfolio on Functional Gastrointestinal Disorders and Motility Disorders.

Digestive Disease Commission

In 1976, Congress enacted Public Law 94-562, which created a National Commission on Digestive Diseases. The Commission was charged with assessing the state of digestive diseases in the United States, identifying areas in which improvement in the management of digestive diseases can be accomplished and to create a long-range plan to recommend resources to effectively deal with such diseases.

The DDNC recognizes the creation of the National Commission on Digestive Diseases, and looks forward to working with the National Commission to address the numerous digestive disorders that remain in today's diverse population.

Conclusion

The DDNC understands the challenging budgetary constraints and times we live in that this Subcommittee is operating under, yet we hope you will carefully consider the tremendous benefits to be gained by supporting a strong research and education program at NIH and CDC. Millions of Americans are pinning their hopes for a better life, or even life itself, on digestive disease research conducted through the

National Institutes of Health. Mr. Chairman, on behalf of the millions of digestive disease sufferers, we appreciate your consideration of the views of the Digestive Disease National Coalition. We look forward to working with you and your staff.

Digestive Disease National Coalition

The Digestive Disease National Coalition was founded 30 years ago. Since its inception, the goals of the coalition have remained the same: to work cooperatively to improve access to and the quality of digestive disease healthcare in order to promote the best possible medical outcome and quality of life for current and future patients with digestive diseases.

PREPARED STATEMENT OF THE DYSTONIA MEDICAL RESEARCH FOUNDATION

Summary of recommendations for fiscal year 2012:

- \$35 Billion for the National Institutes of Health (NIH) and concurrent percentage increases across its institutes and centers.
- Expand dystonia research at NIH through the National Institute on Neurological Disorders and Stroke (NINDS), the National Institute on Deafness and other Communication Disorders (NIDCD), the National Eye Institute (NEI), and the National Institute on Child Health and Human Development (NICHD).
- Continue to advance dystonia research through partnerships with the Office of Rare Diseases Research (ORDR) and the Rare Diseases Clinical Research Network (RDCRN).
- \$100 million for the Cures Acceleration Network (CAN)

Dystonia is a neurological movement disorder characterized by involuntary muscle spasms that cause the body to twist, repetitively jerk, and sustain postural deformities. Focal dystonia affects specific parts of the body, while generalized dystonia affects multiple parts of the body at the same time. Some forms of dystonia are genetic but dystonia can also be caused by injury or illness. Although dystonia is a chronic and progressive disease, it does not impact cognition, intelligence, or shorten a person's life span. Conservative estimates indicate that between 300,000 and 500,000 individuals suffer from some form of dystonia in North America alone. Dystonia does not discriminate, affecting all demographic groups. There is no known cure for dystonia and treatment options remain limited.

Although little is known regarding the causes and onset of dystonia, two therapies have been developed and proved particularly useful to control patients' symptoms. Botulinum toxin (Botox/Myobloc) injections and deep brain stimulation (DBS) have shown varying degrees of success alleviating dystonia symptoms. Until a cure is discovered, the development of management therapies such as these remains vital, and more research is needed to fully understand the onset and progression of the disease in order to better treat patients.

Dystonia Research at the National Institutes of Health (NIH)

Currently, dystonia research at NIH is conducted through the National Institutes on Neurological Disorders and Stroke (NINDS), the National Institute on Deafness and Other Communication Disorders (NIDCD), the National Eye Institute (NEI), and the Office of the Director.

The majority of dystonia research at NIH is conducted through NINDS. NINDS has utilized a number of funding mechanisms in recent years to study the causes and mechanisms of dystonia. These grants cover a wide range of research including the genetics and genomics of dystonia, the development of animal models of primary and secondary dystonia, molecular and cellular studies in inherited forms of dystonia, epidemiology studies, and brain imaging. DMRF works to support NINDS in conducting critical research and advancing the understanding of dystonia.

NIDCD has funded many studies on brainstem systems and their role in spasmodic dysphonia. Spasmodic dysphonia is a form of focal dystonia which involves involuntary spasms of the vocal cords causing interruptions of speech and affecting voice quality. In addition, NEI focuses some of its resources on the study of blepharospasm. Blepharospasm is an abnormal, involuntary blinking of the eyelids which can cause blindness due to a patient's inability to open their eyelids. DMRF encourages partnerships between NINDS, NIDCD and NEI to further dystonia research.

When ORDR initiated the second phase of the Rare Disease Clinical Research Network at NIH, they provided funding for an additional 19 grants aimed at studying the natural history, epidemiology, diagnosis, and treatment of rare diseases. This includes the Dystonia Coalition, which facilitates collaboration between researchers, patients, and patient advocacy groups to advance the pace of clinical research on cervical dystonia, blepharospasm, spasmodic dysphonia, craniofacial

dystonia, and limb dystonia. Working primarily through NINDS and ORDR, the RDCRN holds great hope for advancing understanding and treatment of primary focal dystonias.

Treatment for dystonia is highly individualized, and many dystonia patients do not respond to the current available therapies. The study of potential dystonia therapies is critical for the community. The Cures Acceleration Network (CAN) promises to advance the development of “high need cures,” particularly by reducing the barriers between research discovery and clinical trials in areas that the private sector is unlikely to pursue in an adequate or timely way. DMRF supports this initiative and asks that it be funded at \$100 million, as requested in the President’s budget.

In summary, the DMRF recommends the following for fiscal year 2012:

- \$35 billion for NIH and a proportional increase for its Institutes and Centers.
- Increased portfolio of dystonia research at NIH through the National Institute on Neurological Disorders and Stroke, the National Institute on Deafness and Other Communication Disorders, the National Eye Institute, and the National Institute on Child Health and Human Development.
- Continued partnerships on dystonia research between the Office of Rare Diseases Research, other NIH Institutes and Centers, the Rare Diseases Clinical Research Network, and the dystonia patient community.
- \$100 million for the Cures Acceleration Network

The Dystonia Medical Research Foundation (DMRF)

The Dystonia Medical Research Foundation was founded over 30 years ago and has been a membership-driven organization since 1993. Since our inception, the goals of DMRF have remained to advance research for more effective treatments of dystonia and ultimately find a cure; to promote awareness and education; and support the needs and well being of affected individuals and their families.

Thank you for the opportunity to present the views of the dystonia community, we look forward to providing any additional information.

PREPARED STATEMENT OF THE ELDER JUSTICE COALITION

The Elder Justice Coalition (EJC) thanks you for providing an opportunity to submit testimony as you consider an fiscal year 2012 Labor-HHS and Education Appropriations bill. The EJC is a 705 member strong, non-partisan organization dedicated to advocating for funding for the Elder Justice Act (EJA), a bipartisan bill authored by Rep. Pete King (NY) and sponsored by Rep. Tammy Baldwin (WI) and Rep. Janice Schakowsky (IL). Senator Orrin Hatch (UT) was the sponsor of the Senate version of the bill. The EJA was passed over a year ago. Authorized funding for the EJA is \$195 million per year for 4 years, but first time funding has yet to be appropriated.

Since passage of the EJA, a year later, vulnerable older adults who should be protected by the law are confronted with the same threats they faced a year ago. This is a sad reality given the increasing severity of elder abuse in this country. The most recent study estimates that 14.1 percent of non-institutionalized older adults nationwide had experienced some form of elder abuse in the past year. According to a recent National Institute of Justice study, almost 11 percent of people ages 60 and older (5.7 million) faced some form of elder abuse in 2009. Financial exploitation of older adults is increasingly alarming. A 2009 report by the MetLife Mature Market Institute and the National Committee for the Prevention of Elder Abuse (NCPEA) estimates that seniors lose a minimum of \$2.5 billion each year. A study of financially exploited older persons in one State found that 9 percent of the victims had to turn to Medicaid for their care after their own funds were stolen. Elder financial exploitation undoubtedly represents a large drain on Medicaid throughout the country.

In his proposed budget for fiscal year 2012, President Obama included \$21.5 million for Elder Justice Act funding. The proposed funding would benefit States and local communities and create jobs. Of the \$21.5 million, \$16.5 million was included for State adult protective services, the first and front line responders to cases of elder abuse in the home. Of these funds, \$1.5 million would be used to prevent and address elder abuse within Tribal nations.

APS workers are faced with increasing and complex caseloads while both Federal and State funding for these programs lag behind. Currently, there is no dedicated Federal funding stream for State APS agencies. A recently released report outlines the challenges APS faces and notes that Federal leadership on elder abuse prevention is lacking. Another report points to an overall increase in calls to adult protec-

tive services. Over \$100 million is authorized for State APS programs in fiscal year 2012 and we urge the Subcommittee to use the President's budget proposal, \$21.5 million, as the minimum amount for APS funding. Strengthening APS will enhance its ability to protect both older victims and their assets before it is too late.

The President also included an increase of \$5 million for the Long-Term Care Ombudsman Program to improve resident advocacy to elders and adults with disabilities who reside in a long-term care setting. The Long-Term Care Ombudsman Program is a critical tool in the fight against elder abuse yet, consistently underfunded.

We urge you to include a minimum appropriation of \$21.5 million for the Elder Justice Act in your fiscal year 2012 Labor-HHS Appropriations bill. We thank you for your consideration and please feel free to contact me with questions or concerns.

PREPARED STATEMENT OF THE ELDERCARE WORKFORCE ALLIANCE

Mr. Chairman and Members of the Subcommittee: We are writing on behalf of the Eldercare Workforce Alliance (EWA), which is comprised of 28 national organizations united to address the immediate and future workforce crisis in caring for an aging America. As the Subcommittee begins consideration of funding for programs in fiscal year 2012, the Alliance¹ asks that you consider \$54.9 million in funding for the geriatrics health professions and direct-care worker training programs that are authorized under Titles VII and VIII of the Public Health Service Act as follows: \$46.5 million for Title VII Geriatrics Health Professions Programs; \$3.4 million for direct care workforce training; and \$5 million for Title VIII Comprehensive Geriatric Education Programs.

Geriatrics health profession and direct-care worker training programs are integral to ensuring that America's healthcare workforce is prepared to care for the Nation's rapidly expanding population of older adults.

The first of the baby boomers began to turn 65 this year. Within 20 years, one in five Americans will be over 65; 90 percent of those Americans will have one or more chronic conditions. Despite the growing need for services, there is a growing shortage of health professionals and direct-care workers with specialized training in geriatrics and an even greater shortage of the geriatrics faculty needed to train the entire workforce.

In 2008, the Institute of Medicine (IOM) issued a ground-breaking report, *Retooling for an Aging America: Building the Health Care Workforce*, which spotlighted these shortages and their impact on eldercare. The report called for an expansion of geriatrics faculty development awards to include additional professional disciplines, increased training for the direct-care workforce, and other efforts to create a healthcare workforce with adequate capacity to care for older adults. The Eldercare Workforce Alliance was established to encourage policymakers to act on the IOM's recommendations for addressing the eldercare workforce crisis.

The enactment of the Patient Protection and Affordable Care Act (ACA) was a historic moment for healthcare in this country. ACA makes important strides toward addressing the severe and growing shortages of healthcare providers with the skills and training to meet the unique healthcare needs of our Nation's growing aging population.

ACA includes provisions from the Retooling for an Aging America Act (S. 245 and H.R. 468 in the 111th Congress), sponsored by Senator Kohl (D-WI) and Representative Schakowsky (D-IL). These provisions enhance existing and establish new geriatrics programs in an effort to build the capacity of the healthcare workforce needed to care for older adults, as recommended in the IOM report.

We very much appreciate the funding for the Title VII Geriatrics Health Professions programs that President Obama included in his fiscal year 2012 budget. We urge you to appropriate adequate funds for geriatrics training programs in fiscal year 2012 so that we can immediately begin to realize the healthcare workforce goals set forth in health reform. Specifically, the Eldercare Workforce Alliance requests \$54.9 million in total funding for the following programs under Title VII and VIII of the Public Health Service Act:

Title VII Geriatrics Health Professions Appropriations Request: \$46.5 Million

Title VII Geriatrics Health Professions programs are the only Federal programs that: (1) increase the number of faculty with geriatrics expertise in a variety of dis-

¹ The positions of the Eldercare Workforce Alliance reflect a consensus of 75 percent or more of its members. This testimony reflects the consensus of the Alliance and does not necessarily represent the position of individual Alliance member organizations.

ciplines; and (2) offer critically important geriatrics training to the entire healthcare workforce.

—*Geriatric Academic Career Awards (GACA).*—The goal of this program is to promote the development of academic clinician educators in geriatrics.

Program Accomplishments.—In Academic Year 2009–2010, GACA funded 84 non-competing continuation awards. GACA awardees provided approximately 60,000 health professionals with interdisciplinary geriatrics training. In turn, these trainees provided culturally competent quality healthcare to over 525,000 underserved and uninsured patients in acute care services, geriatric ambulatory care, long-term care, and geriatric consultation services settings.

In 2010, HRSA expanded the awards to be available to more disciplines. EWA advocated for this expansion and we now want to ensure that there is adequate funding for this vital program. Our request of \$5.3 million, as reflected in the President's budget, includes necessary support for 68 Geriatric Academic Career Awardees, promoting the development of clinician educators.

—*Geriatric Education Centers (GEC).*—The goal of the Geriatric Education Centers is to provide quality interdisciplinary geriatric education and training to geriatrics specialists and non-specialists, including family caregivers and direct care workers.

Program Accomplishments.—In Academic Year 2009–2010, the GEC grantees provided clinical training to 54,167 health professional students and to 20,791 interdisciplinary teams in multiple settings.

As part of the ACA, Congress authorized a supplemental grant award program that will train additional faculty through a mini-fellowship program. The program requires awarded faculty to provide training to family caregivers and direct care workers. Our funding request of \$22.7 million, as reflected in the President's budget plus \$2.7 million for the supplemental grants, includes support for the core work of 45 GECs and for the 24 GECs that would be funded to undertake development of mini-fellowships under the supplemental grants program included in ACA.

—*Geriatric Training Program for Physicians, Dentists, and Behavioral and Mental Health Professions.*—The goal of the GTPD is to increase the supply of quality and culturally competent geriatric clinical faculty and to retrain mid-career faculty in geriatrics. This program supports training additional faculty in medicine, dentistry, and behavioral and mental health so that they have the expertise, skills and knowledge to teach geriatrics and gerontology to the next generation of health professionals in their disciplines.

Program Accomplishments.—In Academic Year 2009–2010, 11 non-competing continuation grants were supported. Forty-nine physicians, dentists, and psychiatric fellows received support to provide geriatric care to 20,078 older adults across the care continuum. Geriatric physician fellows provided healthcare to 12,254 older adults. Geriatric dental fellows provided healthcare to 4,073 older adults. Geriatric psychiatry fellows provided healthcare to 3,751 older adults.

Our funding request of \$8.5 million, as reflected in the President's budget, includes support for 13 institutions to continue this important faculty development program.

—*Geriatric Career Incentive Awards Program.*—Congress has authorized this new program created through the ACA, which offers grants to foster greater interest among a variety of health professionals in entering the field of geriatrics, long-term care, and chronic care management. President Obama included \$10 million in his fiscal year 2012 budget to establish this awards program. Our funding request of \$10 million, as reflected in the President's budget, includes support for implementation of this new program.

Title VII Direct-Care Worker Training Program Appropriations Request: \$3.4 million

Direct-care workers help older adults who need long-term services and supports including assistance with activities of daily living (e.g. eating, bathing, dressing, toileting). Expanded training opportunities for these essential workers are critical to ensuring an adequate geriatrics workforce. According to current employment projections, more than 1 million new direct care workers will be needed by 2018 in order to meet the growing need for care.

—*Training Opportunities for Direct Care Workers.*—As part of the ACA, Congress approved an advanced training program for direct care workers, administered by HHS. Although President Obama's budget did not include this vital training program, EWA urges Congress to fund it in order to enhance direct care worker skills and knowledge, and thereby, improve the quality of care for older adults. EWA's funding request of \$3.4 million includes support to establish this unique

grant program at community colleges as they look to increase the geriatrics knowledge and expertise of the direct care workforce.

Title VIII Geriatrics Nursing Workforce Development Programs Appropriations Request: \$5 million

These programs, administered by the HRSA, are the primary source of Federal funding for advanced education nursing, workforce diversity, nursing faculty loan programs, nurse education, practice and retention, comprehensive geriatric education, loan repayment, and scholarship.

—*Comprehensive Geriatric Education Program.*—The goal of this program is to provide quality geriatric education to individuals caring for the elderly. This program supports additional training for nurses who care for the elderly; development and dissemination of curricula relating to geriatric care; and training of faculty in geriatrics. It also provides continuing education for nurses practicing in geriatrics.

Program Accomplishments.—In Academic Year 2009–2010, 27 CGEP grantees provided education and training to [suggest adding all of these together—total of x professionals in nursing, home health, as well as lay people] 3,030 Registered Nurses/Registered Nursing Students; 260 Advanced Practice Nurses; 221 Faculty; 110 Home Health Aides; 483 Licensed Practical/Vocational Nurses & LPN students; 730 Nurse Assistants/Patient Care Associates; 810 Allied Health Professionals and 929 lay persons, guardians, activity directors. The CGEP grantees provided 459 educational course offerings in the care of the elderly on a variety of topics to 6,846 participants.

—*Traineeships for Advanced Practice Nurses.*—Through the ACA, the Comprehensive Geriatric Education Program is being expanded to include advanced practice nurses who are pursuing long-term care, geropsychiatric nursing or other nursing areas that specialize in care of elderly.

Our funding request of \$5 million, as reflected in the President's budget, includes funds that will continue the training of nurses caring for the elderly and offer 200 traineeships to nurses under the newly implemented traineeship program.

Without additional funds in these programs, we will fail to ensure that America's healthcare workforce will be prepared to care for older Americans. We understand that the Committee faces difficult budget decisions. However, we strongly believe that by investing in these programs, which create geriatrics faculty and offer the training that is needed to ensure a competent workforce, we will be delivering better care to America's older adults. Healthcare dollars will be saved from better care coordination and health outcomes, and the workforce will grow as more people are trained, recruited and retained in the field of geriatrics.

On behalf of the members of the Eldercare Workforce Alliance, we commend you on your past support for geriatric workforce programs and ask that you join us in expanding the geriatrics workforce at this critical time—for all older Americans deserve quality of care, now and in the future.

Thank you for your consideration.

PREPARED STATEMENT OF THE FSH SOCIETY, INC.

Honorable Senator Harkin, Mr. Chairman, Honorable Senator Shelby, Ranking Member, Subcommittee members and members of the U.S. Senate Appropriations Committee, Subcommittee on Labor, Health and Human Services, Education and Related Agencies thank you for the opportunity to submit this testimony.

I am Daniel Paul Perez, of Bedford, Massachusetts, President and CEO of the FSH Society, Inc. and an individual who has lived with facioscapulohumeral muscular dystrophy (FSHD) for 48 years. FSHD is also known as facioscapulohumeral muscular disease, FSH muscular dystrophy and Landouzy-Dejerine muscular dystrophy. For hundreds of thousands of men, women, and children the major consequence of inheriting the most prevalent form of muscular dystrophy is a lifelong progressive and severe loss of all skeletal muscles. FSHD is a crippling and life shortening disease. No one is immune, it is genetically and spontaneously (by mutation) transmitted to children and it affects entire family constellations.

My testimony seeks to address the urgent need for NIH to redress and increase funding for research on FSHD.

A consortium of European partners known as Orphanet, led by the French government research agency, INSERM (Institut National de la Santé et de la Recherche Médicale), that is comparable to the United States. NIH, which includes both government and private members, has issued new epidemiology and prevalence data

for hundreds of diseases that ranks FSHD as the first and most prevalent muscular dystrophy. The “Orphanet Series” report November 2010, “Prevalence of Rare Diseases” report can be found at Internet web site: (http://www.orpha.net/orphacom/cahiers/docs/GB/Prevalence_of_rare_diseases_by_alphabetical_list.pdf). FSHD is presented as the third most prevalent muscular dystrophy in the Muscular Dystrophy Community Assistance, Research and Education Amendments of 2001 and 2008 (the MD-CARE Act). This new data changes the findings as listed in the MD-CARE Act. FSHD is 40 percent more prevalent than Duchenne muscular dystrophy (DMD), now recognized as the second most prevalent dystrophy.

Estimated Prevalence	Cases/100,000
Facioscapulohumeral muscular dystrophy (FSHD)	7
Duchenne (DMD) and Becker dystrophy (BMD)	5
Steinert myotonic dystrophy (DM)	4.5

Figures from the online NIH database RCDC RePORT and the NIH Appropriations History for Muscular Dystrophy report provided by NIH/OD Budget Office & NIH OCPL show that from the inception of the MD CARE Act 2001, funding has more than quadrupled from \$21 million to \$86 million in fiscal year 2010 for muscular dystrophy. In fiscal year 2010, total muscular dystrophy funding grew by 3.6 percent (\$3 million/\$83 million) over the previous fiscal year.

In fiscal year 2010, FSHD funding represented 7 percent of the NIH-wide muscular dystrophy budget (\$6 million/\$86 million). In the previous year, FSHD represented 6 percent of the total muscular dystrophy funding (\$5 million/\$83 million). FSHD funding as a percentage of overall NIH muscular dystrophy funding has been level over the last 9 years.

NATIONAL INSTITUTES OF HEALTH (NIH) FSHD FUNDING AND APPROPRIATIONS

[Dollars in millions]

Fiscal Year	FSHD Research	FSHD as a Percentage of Total NIH Muscular Dystrophy Funding
2006	\$1.7	4
2007	3	5
2008	3	5
2009	5	6
2010	6	7

Sources: NIH/OD Budget Office & NIH OCPL & NIH RCDC RePORT.

We highly commend the NIH on the ease of use and the continued accuracy of the Research Portfolio Online Reporting Tool (RePORT) report “Estimates of Funding for Various Research, Condition, and Disease Categories (RCDC)” with respect to reporting projects on muscular dystrophy.

Now that FSHD has been established as the most prevalent muscular dystrophy, and in light of recent advances in research it makes no sense that FSHD remains the most underfunded dystrophy by the NIH and in the Federal research agency system (CDC, DOD and FDA). Given FSHD’s prevalence, disease burden, the overall percentage of funding of the muscular dystrophy research portfolio and major mechanistic breakthroughs on FSHD etiology in 2010 and 2011, we ask Congress to urge NIH to provide a catalyst for scientific opportunity in FSHD.

Inter-dystrophy funding changes and comparisons year after year clearly depicts that NIH FSHD funding needs to be increased and set right. Intra-dystrophy funding changes are misleading as a large change in a small number is still an anemic amount. In fiscal year 2010, the most prevalent muscular dystrophy, FSHD, received a \$1 million increase from NIH to \$6 million, up 20 percent from \$5 million. In fiscal year 2010, the second most prevalent, Duchenne (DMD/BMD) type, received a \$5 million increase from NIH to \$38 million, up 15 percent from \$33 million. In fiscal year 2010, the third most prevalent myotonic dystrophy (DM) type, received \$1 million less from NIH to \$12 million down 8 percent from \$13 million. There is an obvious funding disparity as the first and third most prevalent dystrophies combined, each with major breakthroughs in the past 2 years, are receiving less than half of NIH funding that the second prevalent dystrophy with its disease causing gene being discovered 25 years ago.

The MD CARE Act mandates the NIH Director to intensify efforts and research in the muscular dystrophies, including FSHD, across the entire NIH. It should be very concerning that: (1) in the last 9 years muscular dystrophy has quadrupled to \$86 million and that FSHD has remained on average at 5 percent of the NIH muscular dystrophy portfolio; (2) FSHD, the most prevalent muscular dystrophy is far underrepresented based on percentage of overall NIH dystrophy funding given its prevalence and disease burden; and (3) that both FSHD and DM have had extraordinary major breakthroughs in understanding the disease mechanism in the current and past fiscal years and NIH funding remains level in one and has declined in the other.

(Dollars in millions)

Muscular Dystrophy Type	NIH Funding		Percentage of Total MD funding at NIH	
	Fiscal Year 2009	Fiscal Year 2010	Fiscal Year 2009	Fiscal Year 2010
FSHD	\$5	\$6	6	7
DMD/BMD	33	38	40	44
DM	13	12	16	14

Two major breakthroughs on FSHD occurred in fiscal year 2010 and fiscal year 2011 that make it urgent for the NIH to redress funding for FSHD. On August 19, 2010, a paper titled, "A Unifying Genetic Model for Facioscapulohumeral Muscular Dystrophy" [Science 24 September 2010: Vol. 329 no. 5999 pp. 1650–1653] was published online in the top-rated journal by a group of researchers who started their careers in FSHD research with post-doctoral fellowships from the FSH Society. This paper was a major breakthrough in understanding how FSHD works. It made the front page of the New York Times on the following day. The Times article "Reanimated 'Junk' DNA Is Found to Cause Disease," quoted Dr. Francis Collins, a human geneticist and Director of the National Institutes of Health saying, "If we were thinking of a collection of the genome's greatest hits, this would go on the list." Dr. Collins went on to say, "Well, my gosh, . . . here's a simple disease with an incredibly elaborate mechanism. To come up with this sort of mechanism for a disease to arise—I don't think we expected that." Professor David E. Housman, FSH Society Scientific Advisory Committee Chairman and a geneticist at Massachusetts Institute of Technology (M.I.T.), was quoted saying, "Scientists will now be looking for other diseases with similar causes, and they expect to find them. As soon as you understand something that was staring you in the face and leaving you clueless, the first thing you ask is, 'Where else is this happening?'"

Two months later, another paper was published that originated with seminal funding from the FSH Society that made a second critical advance in determining the cause of FSHD. "Facioscapulohumeral Dystrophy: Incomplete Suppression of a Retrotransposed Gene" was published in PLoS Genetics, October 28, 2010, that made a second critical advance in FSHD. The research shows that FSHD is caused by the inefficient suppression of a gene that may be normally expressed only in early development. The international team of researchers led by Stephen Tapscott, M.D., Ph.D., a member of the Hutchinson Center's Biology Division thinks that the work will lead to new approaches for therapy and new insights into human evolution of disease.

The international FSHD clinical and research community recently came together at the DHHS NIH Eunice Kennedy Shriver National Institute of Child Health and Human Development (NICHD) Boston Biomedical Research Institute Senator Paul D. Wellstone MD CRC for FSHD. Almost 90 scientists working on FSHD globally met at the 2010 FSH Society FSHD International Research Consortium, held October 21–22, 2010 to identify areas of scientific opportunity in FSHD that need funding. The summary and recommendations of the group state that given the recent developments in our definition of FSHD, that within 1 to 2 years evidence-based intervention strategies, therapeutics, and trials need to be planned and conducted. Our immediate priorities should be to confirm that the DUX4 gene hypothesis is valid. Then we must understand the normal DUX4 function. Finally, we must understand the naturally occurring variability to enable us to manipulate the disease in our favor. We need to be prepared for this new era in the science of FSHD by accelerating efforts in the following 10 areas: Shareable protocols; common and shareable materials and data by the whole community; corroborate and verify DUX4 finding; FSHD alleles in context of population genetics need to be defined; biomarkers; FSHD clinical evaluation scales/systems need to be defined under one agreed standard; Working Groups/animal and mouse model working group consortium;

model systems for mechanistic, intervention work and advancement to clinical trials; Epigenetics/Genetics; clinical trials readiness.

To read the expanded summary and recommendations of the group please go to online file at: <http://www.fshsociety.org/assets/pdf/IRCWorkshop2010WorkingConsensusOfPrioritiesGalley.pdf>.

It is impossible to justify the current low level of FSHD funding in the current context of muscular dystrophy budget at the NIH. We have worked hard with our scientific colleagues and member patients and families to build the corpus of knowledge to understand FSHD. We have made great progress in understanding our own disease. We have worked side by side with the NIH directors, program and legislative staff the whole distance to these remarkable discoveries. Still, there has been a confounding and recalcitrant lack of traction at NIH for funding in FSHD. Our request to the NIH—increase FSHD funding now!

NIH constantly reminds us that the NIH system of peer-review delivers the best science from investigator initiated grant applications, thus delivering quality science to the American taxpayer. NIH is receiving more and more grant applications on FSHD. As a nonprofit volunteer health agency that funds breakthrough research based on peer-review mechanics and on a shoe-string compared to NIH, we appreciate the need for peer review, the need to fund the best science and also the need to recalibrate the process to ensure that pragmatic and necessary choices are being pursued in the advent of paradigmatic changes in a disease. We FSHD patients and fellow citizens appreciate this as taxpayers as well.

What it comes down to is—the choice of “the best science” in a disease area and how this has been achieved. This is difficult to measure except in hindsight e.g. what hypotheses represent the best science. The Director of NIH said, set this down, take note, this is 1 of the 10 greatest discoveries in human genomics and that we never expected diseases to be caused by unwanted RNA from reanimated junk DNA. The implications are enormous. FSHD has an incredibly elaborate mechanism that we did not expect. We now know that inadvertent expression of DUX4 from a stretch of reactivated “junk-DNA” causes muscle disease known as FSHD. It is clear that this type of research does not and has not done well in peer-review and it is obvious by the fact that funding is dwarfed. Looking back at the recent NIH Request For Proposals (RFAs) that covered FSHD we can see that all of the breakthrough D4Z4 DUX4 gene grant applications went unfunded by NIH. Perhaps the study sections need to be pulled apart and examined in the broader context of muscular dystrophy. Perhaps comparing Duchenne, Myotonic and FSHD is now much akin to determining the best science in computer science and biology combined. Computer science and biology seems an obvious apples to oranges comparison. We are saddened that the most brilliant work on FSHD was turned away by the NIH. It is crystal clear, if not completely black and white, that FSHD is not achieving the goals of parity in funding as set down in mandates set forth in the MD CARE Acts 2001/2008 and by the NIH Action Plan for the Dystrophies submitted to the Congress by the NIH.

As you know, we are impressed with the efforts of NIH staff and Muscular Dystrophy Coordinating Committee (MDCC) on behalf of the community of patients and their families with muscle disease and the research community pursuing solutions for all of us. We recognize in particular the efforts and hard work of the following NIH staff: Story Landis, Ph.D. and John D. Porter, Ph.D. of National Institute of Neurological Disorders and Stroke (NINDS); Stephen I. Katz, M.D., Ph.D. and Glen H. Nuckolls, Ph.D. and Vittorio Satorelli, Ph.D., National Institute of Arthritis and Musculoskeletal and Skin Disease (NIAMS); James W. Hanson, M.D. and Ljubisa Vitkovic, M.D., Ph.D., (NICHD).

The pace of discovery and numbers of experts in the field of biological science and clinical medicine working on FSHD are rapidly expanding. Many leading experts are now turning to work on FSHD not only because it is one of the most complicated and challenging problems seen in science, but because it represents the potential for great discoveries, insights into stem cells and transcriptional processes and new ways of treating human disease.

We request this year in fiscal year 2012, immediate help for those of us coping with and dying from FSHD. We ask NIH to fund research on facioscapulohumeral muscular dystrophy (FSHD) at a level of \$35 million in fiscal year 2012. In view of the tremendous breakthroughs in FSHD research that may rewrite genetics, we implore the NIH to immediately address the inadequacy in FSHD muscular dystrophy funding.

We implore the Appropriations Committee to request that the Director of NIH, the Chair, and Executive Secretary of the Federal advisory committee MDCC to increase the amount of FSHD research and projects in its portfolios using all available passive and pro-active mechanisms and interagency committees.

We request that NIH be more proactive in facilitating grant applications (unsolicited and solicited) from new and existing investigators and through new and existing mechanisms, special initiatives, training grants and workshops—to bring knowledge of FSHD to the next level.

We ask NIH to consider increasing the scope and scale of the existing DHHS U.S. NIH Senator Paul D. Wellstone Muscular Dystrophy Cooperative Research Centers (U54) to double or triple their size—they are financially under-powered as compared to their potential. These centers have provided an excellent source of human biomaterials and are a catalyst for research, clinical research and training on muscular dystrophy. We ask NIH to develop funding mechanisms to help expand work from NIH Wellstone Centers outward to address needs and priorities of the scientific communities.

We ask NIH for more than one Wellstone center solely dedicated to FSHD. There needs to be one-half dozen groups with 6 to 10 people solely working on FSHD across the United States to assure continuity in FSHD efforts.

We strongly support research discovery through the use of post-doctoral and clinical training fellowships—a model that has worked very effectively for us. It produces results and progeny. Yet, NIH has only a few fellows in dystrophy. We request that NIH issue an RFA to exclusively fund 12 new post-doctoral fellows and four clinical fellows a year on an ongoing basis for the next 5 years on FSHD. We ask that FSHD be the pilot dystrophy for such initiative.

We request that the Director of the NIH initiate solely for FSHD an RFA for Specialized Centers (P50s) to encourage multidisciplinary research approaches on the complexity of FSHD.

We request that the Director of the NIH redress the low level of funding in FSHD by issuing an RFA exclusively for FSHD to allow it to be a prototype disease in the newly forming National Center for Advancing Translational Sciences. This will help advance the translational science in FSHD and catalyze the development of novel diagnostics and therapeutics for FSHD.

We request that the Directors of the NIH develop, through an RFA for FSHD, a central place where clinical trials can be designed and run on animal models of FSHD (mouse, dog, sheep, etc.). It is cost prohibitive to have each U54, P01, P50 funding infrastructure to support these resources. We ask that FSHD be the proof-of-concept disease for such a facility.

Thanks to your efforts and the efforts of your Committee, Mr. Chairman, the Congress, the NIH and the FSH Society are all working to promote progress in FSHD. Our successes are continuing and your support must continue and increase.

Mr. Chairman, thank you for this opportunity to testify before your committee.

PREPARED STATEMENT OF THE FEDERATION OF AMERICAN SOCIETIES FOR
EXPERIMENTAL BIOLOGY

The Federation of American Societies for Experimental Biology (FASEB) urges Congress to make investment in the National Institutes of Health (NIH) an urgent national priority and respectfully requests an appropriation of \$35 billion for the agency in fiscal year 2012. This figure represents an increase that responds to the effects of inflation on the current program level and is needed to continue ongoing initiatives and prevent severe damage to the Nation's capacity for innovation in its fight against disease.

As a federation of 23 scientific societies, FASEB represents more than 100,000 life scientists and engineers, making it the largest coalition of biomedical research associations in the United States. FASEB's mission is to advance health and welfare by promoting progress and education in biological and biomedical sciences, including the research funded by NIH, through service to its member societies and collaborative advocacy. FASEB enhances the ability of scientists and engineers to improve—through their research—the health, well-being, and productivity of all people.

NIH is the driving force behind our Nation's leadership in biomedical science and the dramatic improvements in our health and quality of life. Because of NIH and the research it supports, we stand on the brink of an era of enormous potential progress against the ravages of disease. NIH funds the research of more than 325,000 scientists at over 3,000 universities, medical schools, and other research institutions across the United States. Eighty percent of NIH funding is distributed through competitive grants to researchers in nearly every congressional district and the U.S. territories. More than 130 Nobel Prize winners have received support from the agency. NIH considers many different perspectives in establishing scientific priorities and identifies and, within the limits of its budget, funds the most promising

and highest quality research to address them. NIH is also training the next generation of researchers to ensure that the United States continues to be a global leader in advancing medical science.

Improving Health, Saving Lives

Research funded by NIH has produced an outstanding legacy. NIH-funded discovery has meant that more than 1 million lives per year are saved due to therapies to prevent heart attacks and stroke. That alone has increased American life expectancy by 4 years. Biomedical research discovery has also meant that since 2002 deaths from cancer have steadily declined; and in the past 30 years, survival rates for childhood cancers have increased from less than 50 percent to over 80 percent. More recent advances include:

- Improving Treatments for Acute Myeloid Leukemia (AML).*—Investigators have discovered mutations in a gene that affects the treatment prognosis for some patients with AML, an aggressive blood cancer that kills 9,000 Americans annually. The findings may help guide future treatment strategies for individuals with AML, as well as lead to more effective therapies for patients who carry the mutations.
- Increasing Pediatric Cancer Survival Rates.*—A new form of immunotherapy has significantly improved survival rates of children with neuroblastoma, a deadly nervous system cancer responsible for 12 percent of all cancer deaths in children under age 15. The new therapy has dramatically increased the percentage of children who were alive and free of disease progression after 2 years.
- Reversing Aspects of Aging.*—Researchers have reversed age-related degeneration in a mouse model of aging. While the findings don't prove that natural aging could be halted or reversed, they may lead to new strategies to combat certain age-related conditions.
- Rapidly Detecting Tuberculosis (TB).*—Scientists have developed an automated test that can rapidly and accurately detect TB and drug-resistant TB in patients. The finding could pave the way for earlier diagnosis and more targeted treatment of this disease. TB kills about 1.8 million people each year, and drug-resistant TB is a growing threat. The new test makes it possible to detect TB and drug resistance in a single clinic visit and perhaps begin treatment immediately.

Predictable and Sustainable Funding Will Drive Innovation and Progress

Our leadership in biomedical research has made us the envy of the rest of the world. Our dominant position in the discovery of new drugs and therapies is the result of research conducted by scientists and engineers in academia and in the biotech firms that they have started.¹ A study published in the February 9 issue of the *New England Journal of Medicine* found that 153 new drugs approved by the U.S. Food and Drug Administration during the past 40 years were discovered at least in part by public sector research institutions (universities, research hospitals, nonprofit research institutes, and Federal laboratories), highlighting the increasingly important role of the public sector in the development of pharmaceuticals and other medical interventions.² At present, the NIH budget is insufficient to fund all of the promising research that needs to be done. Less than one in five research proposals can be funded. Over the past 6 years, the number of research project grants funded by NIH has declined in almost every year, and the agency is now funding 2,000 fewer grants than it did in 2004. Due to the extreme competition for support, NIH grant applicants have pared their funding requests to the bare minimum needed to fulfill the goal of their research.

If we fail to continue to capitalize on our investment, others will. We have built laboratories, trained young researchers, and initiated exciting new projects. Potentially revolutionary new avenues of research hold promise for earlier screening and better therapies, but these advances will not become a reality unless the NIH budget is sustained and enhanced to meet inflation's demands. Failure to continue our commitment to biomedical research will terminate important scientific investigations, stunt graduate training, and discourage young scientists who are the key to our future.

The NIH budget is currently \$34 billion (including supplemental appropriations). Exciting new initiatives at NIH are poised to accelerate our progress in the search

¹R. Kneller, *Nature Reviews: Drug Discovery* 9 (November) 2010.

²Ashley J. Stevens, D.Phil., Jonathan J. Jensen, M.B.A., Katrine Wyller, M.B.E., Patrick C. Kilgore, B.S., Sabarni Chatterjee, M.B.A., Ph.D., and Mark L. Rohrbaugh, Ph.D., J.D. The Role of Public-Sector Research in the Discovery of Drugs and Vaccines, *New England Journal of Medicine*, February 9, 2011.

for cures, and it would be tragic if we could not capitalize on the many opportunities before us. A modest increase over the current program level is needed to continue ongoing initiatives and prevent severe damage to our capacity for innovation. Maintaining our current level of effort requires an increase equal to the biomedical research and development price index (BRDPI), which the Bureau of Economic Analysis in the U.S. Department of Commerce estimates will be 3 percent in fiscal year 2012.

A small fraction of our Federal budget, research funding generates an enormous return in new technologies and improved quality of life. Boom and bust cycles are wasteful and inefficient strategies for funding science. The Nations medical research agency needs sustainable and predictable budget growth to maximize the return on this investment in the health and longevity of all Americans. To that end, FASEB recommends an appropriation of \$35 billion for NIH in fiscal year 2012. Thank you for the opportunity to offer FASEB's support for NIH.

PREPARED STATEMENT OF FRIENDS OF THE HEALTH RESOURCES AND SERVICES
ADMINISTRATION

The Friends of HRSA is a nonprofit and non-partisan alliance of more than 180 national organizations, collectively representing millions of public health and healthcare professionals, academicians and consumers. The coalition's principal goal is to ensure that HRSA's broad health programs have continued support in order to reach the populations presently underserved by the Nation's patchwork of health services.

HRSA operates programs in every State and territory and thousands of communities across the country and is a national leader in providing health services for individuals and families. The agency serves as a health safety net for the medically underserved, including the 50 million Americans who were uninsured in 2009 and 60 million Americans who live in neighborhoods where primary healthcare services are scarce. To respond to these challenges, it is the best professional judgment of the members of the Friends of HRSA that the agency will require an overall funding level of at least \$7.65 billion for fiscal year 2012.

While we recognize the reality of the current fiscal climate, our request of \$7.65 billion represents the minimum amount necessary for HRSA to continue to meet the healthcare needs of the American public. Anything less will undermine the efforts of HRSA programs to improve access to quality healthcare for millions of our neediest citizens. Additionally, the Friends of HRSA coalition members remain concerned about the deep cuts made to the agency in the final fiscal year 2011 Continuing Resolution and the negative consequences for public health. Therefore, the requested minimum level of funding for fiscal year 2012 is essential to allow the agency to carry out critical public health programs and services that reach millions of Americans, including training for public health and healthcare professionals, providing primary care services through community health centers, improving access to care for rural communities, supporting maternal and child healthcare programs, and providing healthcare to people living with HIV/AIDS. However, much more is needed for the agency to achieve its ultimate mission of ensuring access to culturally competent, quality health services; eliminating health disparities; and rebuilding the public health and healthcare infrastructure.

Our \$7.65 billion fiscal year 2012 HRSA funding request is based upon recommendations provided by coalition members to support HRSA programs including:

- Health Professions programs support the education and training of primary care physicians, nurses, dentists, dental hygienists physician assistants, nurse practitioners, public health personnel, mental and behavioral health professionals, optometrists, pharmacists, and other allied health providers; improve the distribution and diversity of health professionals in medically underserved communities; and ensure a sufficient and capable health workforce able to provide care for all Americans and respond to the growing demands of our aging and increasingly diverse population. In addition, the Patient Navigator Program helps individuals in underserved communities, who suffer disproportionately from chronic diseases, navigate the health system.
- Primary Care programs support community health centers operating in more than 8,000 communities in every State and territory, improving access to cost-effective and high-quality primary and preventive care in rural and urban underserved areas. In addition, the Health Centers program targets the country's most vulnerable populations, including migrant and seasonal farm workers, homeless individuals and families, and those living in public housing.

- Maternal and Child Health Flexible Maternal and Child Health Block Grants, Healthy Start and other programs provide services, including prenatal and post-natal care, newborn screening tests, immunizations, school-based health services, mental health services, and well-child care for more than 34 million uninsured and underserved women and children not covered by Medicaid or the Children's Health Insurance Program, including children with special needs.
- HIV/AIDS programs provide assistance to metropolitan and other areas most severely affected by the HIV/AIDS epidemic; support comprehensive care, drug assistance and support services for people living with HIV/AIDS; provide education and training for health professionals treating people with HIV/AIDS; and address the disproportionate impact of HIV/AIDS on women and minorities.
- Family Planning Title X programs provide reproductive healthcare and other preventive services for more than 5 million low-income women at over 4,500 clinics nationwide. These programs improve maternal and child health outcomes, prevent unintended pregnancies, and reduce the rate of abortions.
- Rural Health programs improve access to care for the 60 million Americans who live in rural areas. Rural Health Outreach and Network Development Grants, Rural Health Research Centers, Rural and Community Access to Emergency Devices Program, and other programs are designed to support community-based disease prevention and health promotion projects, help rural hospitals and clinics implement new technologies and strategies, and build health system capacity in rural and frontier areas.
- Special Programs include the Organ Procurement and Transplantation Network, the National Marrow Donor Program the C.W. Bill Young Cell Transplantation Program, and National Cord Blood Inventory. Strong funding would facilitate an increase in organ, marrow, and cord blood transplantation.

Greater investment is necessary to sufficiently fund HRSA services and programs that continue to face increasing demands. We urge you to consider HRSA's role in building the foundation for health service delivery and ensuring that vulnerable populations receive quality health services, while continuing to strengthen our Nation's health safety net programs. By supporting, planning for and adapting to change within our healthcare system, we can build on the successes of the past and address new gaps that may emerge in the future.

We appreciate the Subcommittee's hard work in advocating for HRSA's programs in a climate of competing priorities. The members of the Friends of HRSA thank you for considering our fiscal year 2012 request for \$7.65 billion for HRSA in the fiscal year 2012 Labor, Health and Human Services, Education, and Related Agencies Appropriations bill and are grateful for this opportunity to present our views to the Subcommittee.

PREPARED STATEMENT OF FRIENDS OF THE NATIONAL CENTER ON BIRTH DEFECTS
AND DEVELOPMENTAL DISABILITIES ADVOCACY COALITION

The Friends of NCBDDD Advocacy Coalition recommends that Congress provide at least \$144 million in fiscal year 2012 to sustain the vital programs and activities funded by NCBDDD. Furthermore, we call on Congress to ensure any program modifications do no harm for children and adults currently served by the Center and that funds intended to directly benefit the targeted populations not be diverted.

CDC's National Center on Birth Defects and Developmental Disabilities (NCBDDD) works to prevent birth defects and developmental disabilities and help people with disabilities and blood disorders live the healthiest life possible. It is the only CDC Center whose primary mission is focused on birth defects, disability and blood disorders. 2011 marks the 10th year of the Center's accomplishments.

NCBDDD impacts millions of our Nation's most vulnerable: infants and children, people with disabilities, and people with blood disorders. During times of increasing fiscal constraint, NCBDDD is committed to finding strategic approaches to support and strengthen core public health activities for these vulnerable and underserved populations. Public health is the science and art of preventing disease and disability, promoting physical and behavioral wellness, supporting personal responsibility, and prolonging life in communities where people live, work, and learn. Building upon the latest science and evidence-based research, the Center has identified key priorities to these populations to ensure continued public health advancements are made, as well as demonstrating sound returns on investments.

Child Health and Development—Assuring Child Health

Division of Birth Defects and Developmental Disabilities

Success in this NCBDDD program area includes rapidly translating research findings into prevention strategies that prevent birth defects and developmental disabilities, focusing attention on the importance of early care and special intervention services for children born with a birth defect or developmental disability, and supporting parents in helping their children grow into healthy, safe, productive members of society.

Health and Development for People with Disabilities—Improving the Health of People with Disabilities

Division of Human Development and Disability

This spectrum of NCBDDD activities promotes healthy development and reduces health disparities across the life course for persons with or at risk of disability. Program goals include: Improving the health and developmental outcomes for children, improving the quality of life and life expectancy for people with disabilities, and eliminating health disparities faced by persons of all ages living with disabilities.

Public Health Approach to Blood Disorders

Division of Blood Disorders

The history of NCBDDD activities in this area includes bleeding and clotting disorders, hemoglobinopathies and blood product safety. The future of blood disorders is predicated on building upon our past successes and expanding our public health activities to begin addressing the most prevalent, costly, and debilitating bleeding and clotting disorders.

*CDC's National Center on Birth Defects and Developmental Disabilities (NCBDDD)
Focus on Public Health-Social Impact-Safety Net Need of the Populations Served*

The Friends advocacy coalition calls on congressional appropriators and the administration to continue to focus the Center's programs on outcomes that affect positive public health, positive social impact, and the safety net purpose. These include:

Assuring Child Health

Decrease or eliminate birth defects and developmental disabilities occurring due to known causes.

Improve longer term outcomes of children with birth defects, autism, and other developmental disabilities, and eliminate racial/ethnic disparities in these outcomes.

Identify preventable risk factors of birth defects and developmental disabilities, and develop appropriate interventions to reduce these risks.

Increase early identification and intervention for infants and young children with disabling conditions.

Mediate the impact of poverty on developmental outcomes for young children.

Improving the Health of People with Disabilities

Change individual health behaviors to improve health in children, youth, and adults with disabilities.

Improve healthcare access and screening for children, youth, and adults with disabilities.

Reduce the incidence of secondary conditions by increasing health promotion and wellness interventions for children and adults with disabilities.

Improve public health surveillance systems to track the health, development, and participation of persons with disabilities across the life course.

Implement fully the Section 4302 "Patient Protection and Affordable Care Act" intent, expectations, and requirements in "Understanding Health Disparities: Data Collection and Analysis" including "disability status" as well as Section 5307 "Cultural Competency, Prevention, and Public Health" including "individuals with disabilities training."

Public Health Approach to Blood Disorders

Improve the life expectancy of people with Sickle Cell Disease.

Reduce the morbidity and mortality related to bleeding disorders in women.

Reduce the incidence of DVT/PE, and prevent related mortality and serious morbidity.

Prevent emerging morbidities of people with bleeding disorders.

Positive Outcomes

These outcomes should positively affect several social impact goals to improve the life situation of persons with disabilities and other challenges. These include:

- Seamless, positive, and helpful transitions from one of life's stages to the next stage in life, such as the transition from high school to adulthood and work.
- Promotion and support of independent living in the community—a community participation that encourages and promotes self-direction.
- Continued coordinated efforts to assist parents and consumers make informed medical and life decisions.
- Focused activities with the goal of reducing the severity of disability.

PREPARED STATEMENT OF THE FRIENDS OF THE NATIONAL INSTITUTE ON AGING (NIA)

The Friends of the NIA is a coalition of 50 academic, patient-centered and not-for-profit organizations that conduct, fund or advocate for scientific endeavors to improve the health and quality of life for Americans as we age. As a coalition, we support the continuation and expansion of NIA research activities and seek to raise awareness about important scientific progress in the area of aging research currently sponsored by the Institute.

To ensure that progress in Nation's biomedical, social, and behavioral research is sustained, the Coalition endorses the NIH fiscal year 2012 request, \$31.7 billion, as a floor and joins the Ad Hoc Group for Medical Research in supporting \$35 billion for NIH as a ceiling. Given the unique funding challenges facing the NIA, and the range of promising scientific opportunities in the vast, diverse field of aging research, the Friends of NIA ask the subcommittee to recommend NIA receive \$1.4 billion in fiscal year 2012—an amount endorsed by the Leadership Conference on Aging.

The NIA Mission

Established in 1974, NIA leads the national scientific effort to understand the nature of aging in order to promote the health and well being of older adults. NIA's mission is three-fold: (1) Support and conduct genetic, biological, clinical, behavioral, social, and economic research related to the aging process, diseases and conditions associated with aging, and other special problems and needs of older Americans; (2) Foster the development of research- and clinician-scientists for research on aging; and (3) Communicate information about aging and advances in research on aging with the scientific community, healthcare providers, and the public. The NIA fulfills this mission by supporting both extramural research at universities and medical centers across the United States and intramural research at laboratories in Baltimore and Bethesda, Maryland.

Research Activities and Advances

Adding to its strong record of progress throughout its 37-year history, recent NIA-supported activities and advances have contributed to improving the health and well-being of older people worldwide. Below is a summary of some of these most recent activities and advances.

Alzheimer's Disease

Alzheimer's disease (AD) is the most common cause of dementia in the elderly. Between 2.6 million and 5.1 million Americans aged 65 years and older may have AD, with a predicted increase to 13.2 million by 2050. While researchers have achieved greater understanding of the disease, there is no cure. In light of the exploding aging population, which by 2030 is expected to reach 72 million Americans ages 65 or older, scientists are in a race against time to prevent an unprecedented AD epidemic threatening our older population.

NIA is the lead Federal research agency for Alzheimer's disease (AD). In this regard, the Institute coordinates trans-NIH AD initiatives and encourages collaboration with other Federal agencies and private research entities. As illustration of its leadership role, NIA partnered with the McKnight Brain Research Foundation to support the 2010 Cognitive Aging Summit. This meeting, a follow-up to a 2007 summit, brought together experts in a variety of research fields to discuss advances in understanding brain and behavioral changes associated with normal aging, including clinical translational research for prevention of age-related cognitive decline.

As part of its ongoing AD Neuroimaging Initiative (ADNI), the largest public-private partnership currently in AD research, NIA-funded researchers continued to make important progress in 2010. Phase two is underway to define changes in brain structure and function as people transition from normal cognitive aging to mild cognitive impairment (MCI is often a precursor to Alzheimer's) to AD. Using imaging techniques and biomarker measures in blood and cerebrospinal fluid (CSF), ADNI investigators have already established a method and standard of testing levels of AD characteristic tau and beta-amyloid proteins in the CSF, correlated levels of

these proteins with changes in cognition over time, and determined that changes in these two protein levels in the CSF may signal the onset of mild AD.

Genetic research on AD is also yielding important insights into the disease. In 2009 and 2010, several new candidate risk factors gene, including CR1, CLU, PICALM and SORL1, were identified. Identification of new pathways that contribute to the development of AD will provide novel avenues for drug targeting. As part of another initiative, the AD Translational Initiative, 40 compounds are being studied. In addition, industry partners are considering several compounds that NIH funded in the pre-clinical phase for full-scale clinical testing. In total, NIH currently supports 38 clinical trials, including both pilot and large scale trials, of a wide range of interventions to prevent, slow, or treat AD and/or cognitive decline. Any one or more of these trials may hold the key to curing or preventing this terrible disease.

In a major announcement, revised clinical diagnostic criteria for AD dementia were published in the April 19, 2011 issue of *Alzheimer's & Dementia: The Journal of the Alzheimer's Association*, marking the first time in 27 years clinical diagnostic criteria and research guidelines for earlier stages of AD have been revised. The revised guidelines cover the full spectrum of the disease as it gradually changes over many years. They describe the earliest pre-clinical stages of the disease, mild cognitive impairment, and dementia due to AD's pathology. The guidelines also address the use of imaging and biomarkers in blood and spinal fluid that may help determine whether changes in the brain and those in body fluids are due to AD. The guidelines outline some new approaches for clinicians and provide scientists with more advanced guidelines for moving forward with research on diagnosis and treatments.

Increasing Healthy Life Span

Through its Division of Aging Biology, NIA supports research to improve understanding of the basic biological mechanisms underlying the process of aging and age-related diseases. The program's primary goal is to provide the biological basis for interventions in the process of aging, which is the major risk factor for many chronic diseases affecting older people. Recent significant findings that could help advance understanding of a range of chronic diseases, include the discovery of the drug rapamycin, which has been shown to extend median lifespan in a mouse model. Grantees supported by this program have also identified genetic pathways that regulate the maintenance of the stem cell microenvironment in aging tissues.

In fiscal year 2012, the Institute intends to continue supporting the Interventions Testing Program to extend median and/or maximal life span in a mouse model; an initiative to determine cell fates in various tissues of aged mammals, under both normal and injury conditions; and studies to identify neural, neuroendocrine, and other mechanisms that influence age-related changes in bone metabolism and health.

Behavioral and Social Science Research

The Division of Behavioral and Social Research Program supports social and behavioral research to increase understanding of the aging process at the individual, institutional, and societal levels. Research areas include the behavioral, psychological, and social changes individuals undergo throughout the adult lifespan; participation of older people in the economy, families, and communities; the development of interventions to improve the health and cognition of older adults; and the societal impact of population aging and of trends in labor force participation, including fiscal effects on the Medicare and Social Security programs. The Division also leads numerous trans-NIH behavioral and social science research initiatives, such as the ongoing Behavioral Economics initiatives.

One of the Division's signature projects, the Health and Retirement Study (HRS), is recognized as the Nation's leading source of combined data on health and financial circumstances of Americans over age 50. HRS data have been cited in over 1,700 scientific papers and have informed findings regarding the effects of early-life exposures on later-life health, variables associated with cognitive and functional decline in later life, and trends in retirement, savings, and other economic behaviors. In 2010, NIA expanded the HRS to increase minority representation and conduct genome-wide scans of a subset of participants. Also, in 2010, HRS data were used by scientists who found that older adults who survive hospitalization involving severe sepsis, a serious medical condition caused by an overwhelming immune response to severe infection, are at higher risk for cognitive impairment and physical limitations than older adults hospitalized for other reasons.

Funding Challenges

In November 2010, *Nature* magazine featured an article, "Funding crisis hits U.S. ageing research," describing funding challenges facing the NIA and the field of

aging research. The article reported that “in 2010, a researcher submitting a grant application for any single deadline had only an 8 percent chance of winning funding”—falling from 12 percent in 2009. Dr. Richard Hodes, NIA Director, is quoted as saying the currently funding dilemma “threaten[s] the viability of ageing research” and expresses concern, in particular, about the effect the declining success rates could have on the morale of the next generation of scientists and on their ability to compete successfully for an NIA grant. The dire implications of the Institute’s declining success rates is one reason, among others, that the Friends of NIA ask the Subcommittee to support \$1.4 billion, an increase of \$300 million, for the Institute in fiscal year 2012.

Conclusion

We thank you, Mr. Chairman, and the Subcommittee for supporting the NIA and, again, for the opportunity to express our support for the Institute and its important research.

PREPARED STATEMENT OF FUTURES WITHOUT VIOLENCE

Futures Without Violence, formerly Family Violence Prevention Fund, has worked for 30 years to end violence against women and children around the world, and is proud to be a co-chair the nonpartisan Funding to End Domestic and Sexual Violence Coalition, a coalition of over 30 national organizations committed to domestic violence, dating violence, sexual assault, and stalking. As the National Health Resource Center on Domestic Violence, we provide critical information to thousands of healthcare providers, institutions, domestic violence service providers, government agencies, researchers and policy makers each year. Our public education campaigns, conducted in partnership with The Advertising Council, have shaped public awareness and changed social norms for 15 years.

Violence Against Women Health Initiative (HHS Office of Women’s Health).—I wish to request \$3.375 million for the Violence Against Women Health Initiative as authorized by the Violence Against Women and Department of Justice Reauthorization Act of 2005 (Public Law 109–162); the President’s fiscal year 2012 budget requested \$3 million for this Initiative. The Violence Against Women Health Initiative is a consolidation of two Violence Against Women Act 2005 programs (Grants to Foster Public Health Partnerships and Education and Training of Health Care Providers), and a top LHHS priority by the Funding to End Domestic and Sexual Violence Coalition. The Violence Against Women Health Initiative through the Office of Women’s Health, with additional support by the Administration on Children and Families, provides funding to public health programs that integrate domestic and sexual violence assessment and intervention into basic care, as well as encourages collaborations between healthcare providers, public health programs, and domestic and sexual violence programs. The field is already seeing impressive results. We strongly support the continued need to engage health providers to prevent and respond to violence and abuse. Our other priorities are listed at the end of my testimony.

Domestic and sexual violence is a critical healthcare problem and one of the most significant social determinants of health for women and girls. Nearly one in four women in the United States reports experiencing violence by a current or former spouse or boyfriend at some point in her life, and one in six women reported experiencing a completed sexual assault. The Centers for Disease Control and Prevention (CDC) conservatively estimates that intimate partner rape, physical assault and stalking costs the healthcare system \$8.3 billion annually from direct injuries and services. In addition to the immediate trauma caused by abuse, it contributes to a number of chronic health problems. The CDC classifies violence and abuse as a “substantial public health problem in the United States.”

Children who experience childhood trauma, including witnessing incidents of domestic violence, are at a greater risk of having serious adult health problems including tobacco use, substance abuse, cancer, heart disease, depression and a higher risk for unintended pregnancy. Twenty years of research links childhood exposure to violence with chronic health conditions including obesity, asthma, arthritis, and stroke. It is worth noting that victims, particularly of sexual violence, are linked with obesity. A meta-analysis of research on the impact of adult intimate partner violence finds that victims of domestic violence are at increased risk for conditions such as heart disease, stroke, hypertension, cervical cancer, chronic pain including arthritis, neck and pain, and asthma. In addition to injuries, adult intimate partner violence also contributes to a number of mental health problems including depression and PTSD, risky health behaviors such as smoking, alcohol and substance abuse, and poor reproductive health outcomes such as unintended pregnancy, pregnancy com-

plications, post partum depression, poor infant health outcomes and sexually transmitted infections including HIV.

But early identification and treatment of victims can financially benefit the healthcare system. Initial findings from one study found that hospital-based domestic violence interventions may reduce healthcare costs by at least 20 percent. Preventing abuse or associated health risks and behaviors clearly could have long term implications for decreasing chronic disease and costs. Because of the long-term impact of abuse on a patient's health, the Violence Against Women Health Initiative is integrating assessment for current and lifetime physical or sexual violence exposure and interventions into routine care. Regular, face-to-face screening of patients by skilled healthcare providers markedly increases the identification of victims of intimate partner violence, as well as those who are at risk for verbal, physical, and sexual abuse. Routine inquiry of all patients, as opposed to indicator-based assessment, increases opportunities for both identification and effective interventions, validates violence and abuse as a central and legitimate healthcare issue, and enables providers to assist both victims and their children.

When victims or children exposed to violence and abuse are identified early, providers may be able to break the isolation and coordinate with domestic or sexual violence advocates to help patients understand their options, live more safely within the relationship, or safely leave the relationship. Expert opinion suggests that such interventions in adult health settings may lead to reduced morbidity and mortality. Assessment for exposure to lifetime abuse has major implications for primary prevention and early intervention to end the cycle of violence.

Just as the healthcare system has always played an important role in identifying and preventing other serious public health problems, I believe it can and must play a pivotal role in domestic and sexual violence prevention and intervention. It is clear that by funding these innovative and life-saving health provisions, we can help save the lives of victims of violence and greatly reduce healthcare expenses.

In order to advance necessary and needed health goals, I urge you to fund the following LHHS programs accordingly:

Violence Against Women Health Initiative at \$3.375 million

The existing program, entitled "Project Connect: A Coordinated Public Health Initiative to Prevent Violence Against Women," is working with two southern California tribes and eight States (Arizona, Georgia, Ohio, Iowa, Maine, Michigan, Texas, Virginia) to change how adolescent health, reproductive health, and home visiting programs respond to sexual and domestic violence. The Initiative is developing and distributing education and training materials to respond to abuse across the lifespan. Research demonstrates that women in these programs are at high risk for abuse, and that there are evidence-based interventions that can improve maternal and child health, and decreases the risks for unplanned pregnancy, poor pregnancy outcomes and further abuse. These sites provide much-needed services for women in abusive relationships including historically medically underserved communities that have high rates of domestic and sexual violence, such as rural/frontier areas, immigrant women, and Native Americans. UC Davis School of Medicine is implementing an evaluation plan to measure the effectiveness of both the clinical intervention and policy change efforts.

The approach includes creating and disseminating:

- Enhanced clinical interventions to respond to domestic and sexual violence, including training and supporting materials for providers and health systems,
- Patient education materials on the connection between abuse and their health,
- Policy and systems change at the local, State and national level,
- National training of providers through an eLearning platform,
- Pilot programs to offer basic health services within domestic and sexual violence programs, and
- Evaluation and research on the health impact of abuse and the impact of health-based interventions.

In the first year using fiscal year 2009 funding, the Initiative had a significant impact:

- With over 1,500 providers from 50 clinical sites receiving training, programs serving over 200,000 women will integrate assessment for abuse into routine care and offer help when needed, using an evidence-based and setting-specific clinical intervention.
- New education materials for providers and patients/clients have been developed, including:
- New training curriculum for home visitation programs
- New safety cards for adolescents talking about healthy relationships

- Twelve new video vignettes an electronic distance learning platform that will be used to train providers in adolescent, reproductive and maternal and child health programs nationwide.
 - Coordinated State level teams of public health and domestic and sexual violence partners have been formed to create lasting health policy and coordinated response to victims. Examples of policy change include adding assessment of domestic and sexual violence into statewide nursing guidelines, and improving data collection by adding new questions about domestic and sexual violence to statewide surveillance systems.
- This year, the sites are continuing this work but building on the momentum by:
- Implementing an e-learning platform to train tens of thousands of additional physicians, nurses, and students. Beginning in Spring 2011, the free online CME trainings will be offered to Project Connect sites, as well as national health associations, such as the American College of Obstetricians and Gynecologists.
 - Offering basic health services on site in select domestic and sexual violence programs in each Project Connect site. Program strategies include: utilizing mobile health vans, stationing public health nurses in family violence programs, integrating basic health assessment questions into domestic violence shelter intake, and partnering with local providers for ongoing care.
 - Evaluating the impact of Project Connect's clinical intervention on the health and safety of victims of abuse. In addition to the initiative-wide evaluation of provider behavior change, four sites have partnered with local universities to conduct an in-depth evaluation of the effect that integrating the assessment of domestic and sexual violence into clinical settings has on clients.
 - Disseminating information on best practice models for integration in other States/tribes and service settings. Plans include an educational briefing and development of a report outlining model programs.

Report Language under Centers for Disease Control and Prevention Injury Prevention and Control regarding Domestic and Sexual Violence

In VAWA 2005, Congress approved a program entitled “Research on Effective Interventions to Address Violence Against Women” at \$5 million through CDC and ARHQ to support research and evaluation on effective interventions in the healthcare setting to improve victim's health and safety and prevent initial victimization. This authorized program from Public Law 109–162 has not been funded. The President's fiscal year 2012 budget recommends \$20 million of the Prevention and Public Health Fund go to unintentional injuries through CDC's Injury Prevention and Control. To fulfill the need recognized by the earlier VAWA program, I respectfully recommend the following report language:

“The Committee finds that domestic and sexual violence is a healthcare problem and one of the most significant social determinants of health for women and girls. In addition to the immediate trauma caused by abuse, it contributes to a number of chronic health problems. The CDC classifies violence and abuse as a “substantial public health problem in the United States.” As part of the budget request to fund unintentional injury prevention activities from the Prevention and Public Health Fund, the Committee supports a portion of the funding support the prevention of intentional injuries from lifetime exposure to intimate partner violence, child maltreatment, youth violence, and sexual violence.”

Proposed Report Language under HHS Office of Adolescent Health regarding Teen Dating Violence and Communities of Color

The work by the Office of Adolescent Health to create and administer the Teen Pregnancy Prevention Program in such a short time period has been remarkable. That said, adolescents from communities of color are disproportionately affected by teenage pregnancy, and research also shows that teenage dating violence and abuse are associated with higher levels of teenage pregnancy and unplanned pregnancy. Adolescent girls in physically abusive relationships are three times more likely to become pregnant than non-abused girls. To fulfill the promise of the Office of Adolescent Health to holistically address teen pregnancy prevention, I respectfully recommend the following report language:

“The Committee strongly urges the Secretary, through the Office of Adolescent Health, to include teen dating violence prevention and healthy relationship strategies within existing adolescent health working groups and better integrate preventing violence and abuse as a strategy to prevent teen and unplanned pregnancy within communities of color. Further, the Committee strongly urges the Secretary, though the Office of Adolescent Health, to conduct a review of the evidence-based programs chosen by the Teen Pregnancy Prevention Program and issue a report to

determine which programs address teen dating violence and healthy relationship strategies as a means to prevent teen pregnancy.”

In addition, I ask that you at least meet the President’s fiscal year 2012 request of \$135 million for the Family Violence Prevention and Services Act (FVPSA) under ACF, the Nation’s only designated Federal funding source for domestic violence shelters and services. As we are all committed to both the prevention of violence and abuse and to the health and safety of victims, I urge you to fund these critical programs.

PREPARED STATEMENT OF THE GLOBAL HEALTH TECHNOLOGIES COALITION

Chairman Harkin, Ranking Member Shelby and members of the Committee, thank you for the opportunity to provide testimony on the fiscal year 2012 appropriations funding for the National Institutes of Health (NIH) and the Centers for Disease Control and Prevention (CDC). We appreciate your leadership in promoting the importance of international development, in particular global health. We hope that your support will continue. I am submitting this testimony on behalf of the Global Health Technologies Coalition (GHTC), a group of nearly 40 nonprofit organizations working together to advance U.S. policies which can accelerate the development of new global health innovations—including new vaccines, drugs, diagnostics, microbicides, and other tools—to combat global health diseases. The GHTC’s members strongly believe that to meet the global health needs of tomorrow, it is critical to invest in research today so that the most effective health solutions are available when we need them, and that the U.S. Government has a historic and unique role in doing so. My testimony reflects the needs expressed by our member organizations¹ which include nonprofit advocacy organizations, policy think-tanks, implementing organizations, and many others. One-third of our members are also nonprofit product development partnerships, which work with partners in the private biotechnology and pharmaceutical and medical device sectors, as well as public research institutions, academia, and nongovernmental organizations to develop new and more effective life-saving technologies for the world’s most pressing health issues. We strongly urge the Committee to continue its established support for global health research and development (R&D) by (1) sustaining and protecting the U.S. investment in global health research and product development, (2) instructing NIH and CDC, in collaboration with other agencies involved in global health, to continue their commitment to global health in their R&D programs, and (3) requiring leaders at U.S. agencies to put plans in place to ensure that global health R&D is efficient, coordinated and streamlined.

Critical need for new global health tools

Our Nation’s investments have made historic strides in promoting better health around the world: nearly 6 million people living with HIV/AIDS now have access to life-saving medicines, new, cost-effective tools help us diagnose diseases quicker and more efficiently than ever before, and innovative new vaccines are making significant dents in childhood mortality. While we must increase access to these and other proven, existing health tools to tackle global health problems, it is just as critical that we continue to invest in developing the next generation of tools to stamp out disease and address current and emerging threats. For instance, newer, more robust, and easier to use antiretroviral drugs, particularly for infants and young children, are needed to treat (and prevent) HIV and even a 50 percent effective AIDS vaccine could prevent 1 million HIV infections every year. Drug-resistant tuberculosis is on the rise globally, including in the United States, however the only vaccine on the market is insufficient at 90 years old, and most therapies are more than 50 years old, extremely toxic, and exorbitantly expensive. New tools are also urgently needed for fatal neglected tropical diseases such as sleeping sickness for which diagnostic tools are inadequate, and the few drugs that are available are toxic and difficult to use. There are many very promising technology candidates in the R&D pipeline to address these and other health issues; however, these tools will never be available if the support needed to continue R&D is not protected and sustained.

Research and US global health efforts

The United States is at the forefront of innovation in global health technologies. For example, as recently as December, a new meningitis vaccine costing less than 50 cents per dose developed by the Meningitis Vaccine Project—a partnership be-

¹ GHTC member list: <http://www.ghtcoalition.org/coalition-members.php>.

tween the World Health Organization and the international nonprofit PATH—was distributed for the first time in Africa—the development and implementation of which was supported through strategic funding and scientific expertise from the CDC, NIH, U.S. Food and Drug Administration (FDA), and the U.S. Agency for International Development (USAID).

The NIH is the largest funder of global health research in the U.S. Government, and the agency has recently demonstrated a growing interest in global health issues. NIH Director Francis Collins made global health one of his top five priorities for the future of NIH, stating, “. . . the world has seen us as the soldier to the world. Might we not do better both in terms of our benevolence and our diplomacy by being more of a doctor to the world?”² The NIH’s Fogarty International Center recently began collaborating with the Department of Health and Human Services’ Health Research Services Administration and the U.S. Department of State’s Office of the U.S. Global AIDS Coordinator on the Medical Education Partnership Initiative to develop, expand, and enhance models of medical education. This includes enhancing the capacity of local individuals to conduct research on global health diseases. Also recently, the Therapeutics for Rare and Neglected Diseases (TRND) program at the NIH launched five pilot projects to spur drug development for diseases including schistosomiasis and hookworm. Each of these efforts build on the historic work carried out by the agency which contributes to improved health around the world.

With operations in more than 54 countries, the CDC is engaged in many global health research efforts. The work of CDC scientists has led to major advances against devastating diseases, including the eradication of smallpox and early identification of the disease that became known as AIDS. Although CDC is known for its expertise and participation in HIV, TB, and malaria programs, it also operates several activities for neglected diseases in its National Center for Zoonotic, Vector-Borne, and Enteric Diseases.

Leveraging the private sector for innovation

NIH, CDC, USAID and other agencies involved in global health R&D regularly collaborate with the private sector in developing, manufacturing, and introducing important technologies such as those described above through public-private partnerships, including product-development partnerships. These partnerships leverage public-sector expertise in developing new tools, partnering with academia, large pharmaceutical companies, the biotechnology industry, and governments in developing countries to drive greater development of products for neglected diseases for which private industries have not historically invested. This unique model has generated twelve new global health products and has enormous potential for continued success if robustly supported.

In order to more fully engage the private sector in developing products for global health R&D, additional market-based incentives are needed. With little-to-no commercial drive to develop new drugs and vaccines for diseases that primarily affect the developing world, financial incentives and innovative financing must be pursued. No single incentive scheme or financing mechanism is capable of filling all the gaps and encouraging the full range of R&D activities across all of the diseases and products that the developing world urgently needs. A portfolio of incentives and financing mechanisms that can fill the multiple gaps in the product development pipeline for multiple diseases is needed. NIH should be applauded for its participation in the small business innovation research awards and a patent pool for HIV medicines, and additional efforts in this area are encouraged. The development of new incentive strategies is critical for long-term, meaningful private-sector engagement in global health.

Innovation as a smart economic choice

Global health R&D brings life-saving tools to those who need them most, however the benefits these efforts bring are much broader than preventing and treating disease. Global health R&D is also a smart economic investment in the United States, where it drives job creation, spurs business activity, and benefits academic institutions. Biomedical research, including global health, is a \$100 billion enterprise in the United States. In a time of global financial uncertainty, it is important that the United States support industries, such as global health R&D, which build the economy at home and abroad.

History has shown that investing in global health research not only saves lives but is also a cost-effective approach to addressing health challenges. And an invest-

² NIH all-hands town meeting, 17 August 2009. <http://videocast.nih.gov/Summary.asp?File=15247>.

ment made today can help save significant money in the future. In the United States alone, for example, polio vaccinations during the last 50 years have resulted in a net savings of \$180 billion, funds that would have otherwise been spent to treat those suffering from polio. In addition, new therapies to treat drug-resistant tuberculosis have the potential to reduce the price of tuberculosis treatment by 90 percent and cut health system costs significantly. The United States has made smart investments in research in the past that have resulted in lifesaving breakthroughs for global health diseases, as well as important advances in diseases endemic to the United States. We must now build on those investments to turn those discoveries into new vaccines, drugs, tests, and other tools.

Recommendations

In this time of fiscal constraint, support for global health research that improves the lives of people around the world—while at the same time creating jobs and spurring economic growth at home—should unquestionably be one of the Nation's highest priorities. In keeping with this value, the GHTC respectfully requests that the Committee do the following:

- Sustain and protect U.S. investments in global health research and product development within both the CDC and NIH budgets. We ask that this not come at the expense of robust funding for the entire set of global public health accounts, all of which complement each other and ultimately serve the common goal of building a healthier and more prosperous world.
- Instruct all U.S. agencies in its jurisdiction to continue their commitment to global health in their R&D programs by developing actions plans, including metrics to measure progress. The Committee shall request that leaders at NIH and CDC work with leaders at other U.S. agencies to ensure that efforts in global health R&D are coordinated, efficient, and streamlined by establishing transparency mechanisms designed to show what global health R&D efforts are taking place and how U.S. agencies are collaborating with each other to make efficient use of the U.S. investment.
- Request relevant agencies report on their progress to Congress and be made publicly available. Past accounting of the health R&D activities at individual agencies, such as Research, Condition, and Disease Categorization at NIH, have been very helpful in coordinating efforts between agencies and informing the public and such efforts should be expanded to include neglected disease categorization and extended to provide a comprehensive picture of this investment from all agencies involved in global health R&D.

We respectfully request that the Committee consider inclusion of the following language in the report on the fiscal year 2012 State and Foreign Operations appropriation legislation:

“The Committee recognizes the urgent need for new global health technologies in the fight against global health diseases, and the critical contribution that the NIH, CDC, and FDA make to this cause through their health research and training portfolios, operations research and regulatory capabilities. The Committee also acknowledges the urgent need to sustain and protect U.S. investment in this important research by fully funding these three agencies to carry out their work.

“New global health products such as drugs, vaccines, diagnostics, and devices are cost-effective public health interventions that play an important role in improving global health and are vital in stopping pandemics. The Committee understands the positive impact that global health research and development has on the U.S. economy through the creation of U.S. jobs and the development of foreign markets for U.S. products. NIH is widely recognized as the world leader in basic research, and has supplied invaluable breakthroughs that have led to new health tools, saving millions of lives globally. Through its Fogarty International Center, NIH harnesses its wealth of expertise to train the next generation of health scientists.

“The Committee directs the CDC, FDA, and NIH to each create metrics to measure progress and to develop concrete plans to prioritize and incorporate global health research, product development, and regulation into their U.S. global health and development strategies. The Committee directs CDC, FDA, and NIH to work with each other as well as the Department of State, the U.S. Agency for International Development, and the Office of the U.S. Global AIDS Coordinator to ensure that these efforts are coordinated, efficient, and streamlined across the agencies involved in implementing the President's Global Health Initiative. CDC, FDA, and NIH shall each make the documentation and results of these efforts available to Congress and the public.”

As a leader in science and technology, the United States has the ability to capitalize upon our strengths to help reduce illness and death and ultimately eliminate

disabling and fatal diseases for people worldwide, contributing to a healthier world and a more stable global economy. Sustained investments in global health research to develop new drugs, vaccines, tests, and other health tools—combined with better access to existing methods to prevent and treat disease—present the United States with an opportunity to dramatically alter the course of global health while building political and economic security across the globe.

On behalf of the members of the GHTC, I would like to extend my gratitude to the Committee for the opportunity to submit written testimony for the record.

PREPARED STATEMENT OF GOODWILL INDUSTRIES INTERNATIONAL

Mr. Chairman, Ranking Member, and Members of the Subcommittee, on behalf of Goodwill Industries International® (GII), I appreciate this opportunity to submit written testimony on Goodwill's priorities for fiscal year 2012 funding programs administered by the U.S. Departments of Labor, Health and Human Services, and Education.

Goodwill Industries International (GII) represents 158 local and autonomous Goodwill Industries agencies in the United States that help people with barriers to employment to participate in the workforce. One of Goodwill Industries' greatest strengths continues to be its entrepreneurial approach to sustaining its mission. In 2010, Goodwill raised more than \$4 billion in its retail stores and other social enterprises and invested 84 percent of its privately raised revenues to supplement Federal investments in programs that give people the skills they need to reenter the workforce. Goodwill provided job training, employment services, and supportive services to nearly 2.5 million people, placing more than 170,000 people in jobs and employing 97,000. Nearly 160,000 people were referred to Goodwill from the workforce system or a State Vocational Rehabilitation Agency. In addition to our efforts to help people find jobs and advance in careers, Goodwill understands that many people need additional supportive services—child care, reliable transportation, stable housing, counseling and assistance in adjusting to the workplace, assistive technology—to ensure their success.

Now more than ever, with unemployment slowly declining from the highest levels experienced in a generation, local Goodwill agencies are on the front lines of the fragile recovery assisting people with employment barriers, including individuals with disabilities, older workers, and Temporary Assistance to Needy Families (TANF) recipients who are struggling to find and keep jobs during a stubbornly tight job market. In addition in 2010, Goodwill's collective investment in these services eclipsed the Department of Labor's combined investment in WIA's adult, youth, and dislocated workers.

While Goodwill is proud of these and other achievements, they are truly the result of a public-private partnership. As the fragile recovery from the worst recession since the Great Depression continues and unemployment rates slowly decline from near 10 percent, Goodwill understands the difficult challenge that appropriators face as they struggle to reduce the deficit while stretching limited resources to support an ever-increasing list of national priorities. Reducing the deficit is a serious issue that will require all to make sacrifices to address the Nation's spending problem while investing in integrated strategies that build upon and leverage existing resources that will address our Nation's revenue problem. Therefore, Goodwill was very concerned about the drastic cuts to the workforce system that were proposed in the fiscal year 2011 continuing resolution (H.R. 1) that was passed by the House of Representatives earlier this year, and thanks the Senate for its efforts to mitigate the cuts in the final fiscal year 2011 spending deal. As Congress works to develop its spending bills for fiscal year 2012, Goodwill is again concerned because the House budget allocation for Labor, Health and Human Services, and Education is \$18 billion less than the amount agreed to in the final fiscal year 2011 budget deal.

Goodwill is aggressively moving to increase its capacity to do more to help people find jobs and advance in careers during and after these difficult times. Goodwill is working to open more stores and attended donation centers in order to create jobs and generate more privately raised revenues to invest in people who are facing employment challenges in the communities that local Goodwill agencies serve. In addition, Goodwill is more committed than ever to partnering with stakeholders at the Federal, State, and local levels by contributing the resources and expertise of local Goodwill agencies in support of public efforts and investments.

While our agencies care about a range of Federal funding sources, Goodwill urges Congress to provide funding for the Department of Labor's Senior Community Service Employment Program (SCSEP); the Workforce Investment Act's adult, dislocated

worker, and youth funding streams; summer jobs for youth; and the Department of Education's Vocational Rehabilitation programs.

Senior Community Service Employment Program (SCSEP)

Workers who are 55 and older have multiple barriers to employment and will be among the last rehired as the economy improves. Furthermore, according to the Bureau of Labor Statistics, the unemployment rate for older workers (over 55 years old) was 6.2 percent in April, 2011. While older workers are less likely to be unemployed than their younger counterparts, older workers who do lose their jobs face significant odds of finding another one. The average time spent looking for a job by someone between the ages of 55 and 64 is 44.6 weeks. Those over the age of 64 also spend nearly 1 year seeking work for an average of 43.9 weeks. Older workers are more likely to be laid off from industries that are in structural decline. This population may be less likely to go back to school as they have other financial burdens and are less mobile due to home ownership. Finally, these workers may face age discrimination when applying for a new job. Therefore, Goodwill is alarmed by the Administration's proposal to cut funding for the Community Services Employment for Older Americans program (also called the Senior Community Service Employment Program) by 45 percent which will result in the elimination of services to nearly 50,000 low income older workers who badly in need of assistance.

SCSEP helps provide low-income older workers with community services employment and private sector job placements. Preserving SCSEP funding is critical as it is the only program targeted to helping low income seniors regain employment, as this population is experiencing the toughest employment prospects in a generation. Goodwill is a national SCSEP grantee with providers around the country. While many individuals assume that SCSEP is for much older workers and question the type of training received, 42 percent of Goodwill's SCSEP participants are between the ages of 55 and 59. In 2010, SCSEP participants contributed nearly 1.4 million community service hours and our private sector placements averaged a starting wage of \$9.75 per hour.

In recent years, Congress has demonstrated its commitment to older workers by providing an additional \$120 million for SCSEP in the Recovery Act, and a \$250 million increase in fiscal year 2010. These funds have allowed local Goodwill agencies to better address our waiting list of participants and help many older workers with part-time employment. Private sector placement wages also increased. Goodwill very much appreciates the monumental investment that the Congress has placed on helping older workers to survive the economic crisis. However, as SCSEP program providers prepare for a cut in funding, community service hours have been cut, new enrollees have not been accepted, and additional classroom training that has an added cost have been reduced or eliminated. Should SCSEP be cut further, it will result in a loss of professional staff and it will be more difficult to get out to non-urban areas since rural communities will have fewer slots.

Goodwill urges the Subcommittee to reject the Administration's proposed cuts to SCSEP. At a minimum Congress should fund SCSEP at no less than \$600 million, which will allow a restoration of assistance to an additional 24,000 participants, nearly half of the participants cut from the program by funding reductions in the fiscal year 2011 Continuing Resolution.

Workforce Investment Act

Funding for the Workforce Investment Act's youth, adult, and dislocated worker formulas is one of Goodwill's top funding priorities for fiscal year 2012. Most Goodwill agencies have people referred to them through the workforce system. In addition, several agencies are one-stop lead operators or operators in association with other service providers, and are active on state and local workforce boards.

It should be noted that, in 2002, when the unemployment rate was 5.8 percent, combined funding for WIA's youth, adult, and dislocated worker funding streams was more than \$3.67 billion. Since then, funding has steadily eroded; and nearly 10 years later, at a time when the unemployment rate remains much higher—around 9 percent—the Administration proposes just \$2.96 billion for WIA's three main funding streams, nearly 20 percent less than the fiscal year 2002 level. Furthermore, the Administration proposes to divert 8 percent to contribute to the creation of a Workforce Innovation Fund to “support and test promising approaches to training, and breaking down program silos, building evidence about effective practices, and investing in what works.”

Goodwill believes that a Workforce Innovation Fund is a promising idea, is very interested in the details, and is encouraged by the Administration's efforts to increase interagency collaborations and leverage resources provided by community-based organizations, however the proposed Workforce Innovation Funds should be

paid for with funds in addition to, rather than at the expense of, existing WIA formula funds—in fiscal year 2012 and beyond.

In 2010, the workforce system served more than 8 million people, placing more than half in jobs while helping others to access education and training aimed at improving their future employment prospects. As noted earlier, Goodwill is doing all it can to help people who have been affected by the recession. In fact in 2010, Goodwill's collective investment in job training and employment services eclipsed the Department of Labor's combined investment in WIA's adult, youth, and dislocated workers. Some agencies have, in fact, been doing more than they can by deliberately using their reserves in order to provide help to more people than their current revenues support. If not now, when? Therefore, Goodwill is very concerned the continued delay in reauthorizing WIA may put the whole system at risk, causing many Goodwill agencies to wonder how they would respond to the dramatic increase in requests for services if the workforce system were to be dismantled completely. Most agencies would be forced to turn away people in need or risk being overleveraged to the brink.

Goodwill understands that this Subcommittee faces a difficult challenge in stretching limited resources to cover a range of priorities; however the workforce system is vastly under-funded and preservation of WIA's formula funding streams should be a high priority. Therefore, Goodwill urges Congress to sustain WIA's adult, dislocated worker, and youth funding streams at current funding levels at a minimum. Before diverting funds from WIA's already underfunded programs, Congress should reauthorize WIA and include provisions that would establish the Workforce Innovation Fund without jeopardizing existing funds for WIA's three core funding streams.

Vocational Rehabilitation (VR) Funding

Goodwill Industries has a long history of helping people with disabilities to participate in the workforce despite the challenges their disabilities present. Years of inadequate funding for VR have left the system stretched much too thin to serve all who are eligible for assistance. As a result, most State VR agencies have Orders of Selection, a provision within the Rehabilitation Act that requires State VR agencies, when faced with a shortage of funds to meet the demand for services, to prioritize the provision of services to eligible people based on the severity of people's disabilities. In addition, reduced funding for WIA has placed an additional strain on mandatory partner programs, including VR, which are being asked to contribute more funding to pay for infrastructure and other costs associated with the operation of one-stop centers.

Goodwill supports the Administration's intent to increase multi-system collaboration and support for youth with disabilities who are transitioning from education to the workforce. The Administration's fiscal year 2012 budget proposes to increase funding for VR State agencies by \$57 million, while diverting \$30 million of VR's State grant funds to contribute to a new Workforce Innovation Fund. Funding for the Rehabilitation Services Administration's Migrant and Seasonal Farmworker program, Projects with Industry, and Supported Employment would be eliminated, thus offsetting the increase by \$50 million.

For more than two decades, Goodwill has offered supported employment as a part of its service array. According to Goodwill Industries International's Annual Statistical Report, participation in local Goodwill agencies' supported employment programs has grown dramatically in recent years from providing 270,000 coaching sessions in 2007 to 630,000 sessions in 2009.

Goodwill is intrigued by the Administration's proposal to stimulate system collaboration by creating a Workforce Innovation Fund; however, Goodwill believes that funding for the Workforce Innovation Fund should not come at the expense of existing and already inadequate funds for the VR system.

Goodwill thanks the Subcommittee for considering these requests, and looks forward to working with the Subcommittee to help government meet the serious challenges our nation faces.

PREPARED STATEMENT OF THE HARLEM CHILDREN'S ZONE

Thank you for this opportunity to support comprehensive services for poor children and the U.S. Department of Education's (ED) Promise Neighborhoods program which we believe will break the cycle of generational poverty for hundreds of thousands of poor children.

Like the work at the Harlem Children's Zone® (HCZ®), the Promise Neighborhoods program has already begun to transform the odds for entire communities.

High-achieving schools are at the core of Promise Neighborhoods, but it is not only about creating a successful school. It is about programs for children from birth through college and career, supporting families and rebuilding community. Doing this changes the trajectory of an entire community.

In the mid-1990s it became clear to the HCZ team that despite heroic efforts at saving poor children, success stories remained the exception. Our piecemeal approach was of limited value against a perfect storm of problems and challenges. So the HCZ Project was created in Central Harlem to work with kids, their families and their community. Starting with one building, HCZ has grown to 97 blocks. Last year, the HCZ Project served 15,508 clients including 8,838 youth and 6,670 adults. HCZ, Inc., which includes the HCZ Project plus our Beacon Centers and Preventive Foster Care programs, served 23,556 clients including 10,541 youth and 13,015 adults.

Now, over a decade later, the Children's Zone® model is working. Parents are reading more to their children. Four year olds are ready for kindergarten. Students are closing the black-white achievement gap in several subjects. Teenagers are graduating from high school and this school year, over 600 of them who attended traditional public schools are in college. HCZ helps parents file for taxes including the Earned Income Tax Credit (EITC) and last tax season, families collectively received over \$8 million.

HCZ's theory of change is embodied in the application of all of the following five principles:

- Serve an entire neighborhood comprehensively and at scale.
- Create a pipeline of high-quality programs that starts from birth and continues to serve children until they graduate from college. Provide parents with supports as well.
- Build community among residents, institutions, and stakeholders, who help to create the environment necessary for children's healthy development.
- Evaluate program outcomes; create a feedback loop that cycles data back to management for use in improving and refining program offerings; and hold people accountable.
- Cultivate a culture of success rooted in passion, accountability, leadership, and teamwork.

The HCZ® model is not cheap. On average, HCZ spends \$5,000 per child each year to ensure children's success. For far less money than is already spent, just on incarceration, we can educate, graduate our children, and bring them back to our communities ready to be successful, productive citizens. We think the choice is obvious.

HCZ's achievements are not magic. They are a result of hard work and a comprehensive effort.

This same type of hard work and comprehensive effort is happening in countless communities across the country. To provide a sense of the level of interest in the Promise Neighborhoods program, when the Department of Education offered the first round of planning grants in fiscal year 2010's budget, over 339 communities competed for just 21 grants. Additionally, over 100 of these communities scored over 80, leading Secretary of Education Arne Duncan to note that there would have been more grants if resources were available. Just 7 months later, these communities are going strong. For example:

Buffalo, New York

The Buffalo Promise Initiative, which is led by M&T's Westminster Foundation, is collaborating with the John R. Oishei Foundation, Read to Succeed Buffalo, the City of Buffalo, Buffalo Public Schools, United Way of Buffalo and Erie County, Catholic Charities, Buffalo Urban League, and the University at Buffalo to serve 11,000 residents in a 1-square mile, low-income neighborhood. The Buffalo Promise Initiative is a vital counterpoint to the challenges brought about in Buffalo due to a shift away from industrially focused jobs, a shrinking population, and increasing poverty. A comprehensive approach is blooming, addressing the needs and hopes of children and their families in a changing Buffalo.

Indianola, Mississippi

The Indianola Promise Community (IPC) is located in Indianola, Mississippi, in the heart of the Mississippi Delta and the birthplace of musician B.B. King. The Delta Health Alliance is the lead agency for this unique public policy initiative. The Indianola Promise Community unites healthcare, education, community, and faith-based services to provide Indianola residents the chance to realize their promise as active members and leaders in their town and neighborhoods. The Delta Health Alliance has teamed up with a number of nonprofit organizations and government agen-

cies, including the local school district, the municipal government, Mississippi State University, the county hospital, and the Children's Defense Fund, to develop a comprehensive collaborative with the ability to take on a number of pressing challenges.

Although Indianola has a number of obstacles to overcome, leaders from all aspects of the community have joined together to make the IPC a success. The Delta Health Alliance is integrating more than a dozen of their preexisting services and adding new programs and new partners into a robust set of resources. The goal is to create a set of integrated services for children and their families. The IPC engages with all community service providers to prevent the duplication of resources and highlight service gaps. Community members also serve on the Steering Committee that oversees the work of the project.

Northern Cheyenne Reservation

The rich and deep history of the Northern Cheyenne community and their commitment to engage their members is apparent in their plans to develop a thriving Promise Neighborhood for their community. The Promise Neighborhood is located on the Northern Cheyenne Reservation and the surrounding communities of Colstrip and Ashland in southeast Montana. The land is sprawling, approximately 700 square miles, and approximately 7,300 people live within the Neighborhood.

The Boys and Girls Club of Northern Cheyenne Nation (BGCNCN), the Promise Neighborhood lead partner, believes in "systemic, collaborative, strengths-based and culturally appropriate approaches" to youth and community development that will comprehensively address the disadvantages that the community faces.

The Boys and Girls Club has established relationships with local communities, and thus is an excellent lead partner for this initiative. All of the primary institutions that serve young people in the area are involved in collaborating during this planning year. The Promise Neighborhood has the full support of the Northern Cheyenne government, local schools and agencies, Chief Dull Knife College, and a number of nonprofits. All are working together to specifically create and implement in- and out-of-school strategies and services that will support the academic achievement, healthy development, cultural awareness and connectedness, and college and career success of the Neighborhood's children. Some of the BGCNCN's programs for youth include a Native American Mentoring Program, a diabetes prevention program, leadership groups, and a computer lab. The planning phase has brought these groups together to begin a more concerted effort to assess and develop a pipeline of programs that will benefit the youth and community.

San Antonio, Texas

The Eastside Promise Neighborhood in San Antonio, Texas is led by the United Way and has a strong partnership with the City of San Antonio. San Antonio Mayor Julián Castro and other community leaders are major supporters of the initiative. The Promise Neighborhood initiative is part of the City's larger plan to support the struggling Eastside, including the development of affordable housing, education, environment, and other supports, and developing a strategic framework that speaks to the community's core problems.

The Promise Neighborhood initiative, with its set of partners like the San Antonio Independent School District, Family Service Association, Housing Authority, City Year, Trinity University, San Antonio for Growth on the Eastside (SAGE), and the Urban Land Institute, is working hard to coordinate the supports and resources in the neighborhood to activate their collective vision for community transformation. The planning and coordination of resources going into the community as a part of the Promise Neighborhood initiative fits into the City's broader Eastside Reinvestment Plan aiming to shift away from siloed and uncoordinated services on the Eastside.

Because parents are a key element to their children's success, Eastside Promise Neighborhood has a commitment to parental engagement and capacity-building through focus groups, community meetings during which the community shapes the agenda, and parentally focused career and empowerment groups through initiatives like the United Way's Family-School-Community Partnership.

This asset-based approach and vision ensures more efficient and effective use of neighborhood talent, resources, rich opportunities for young people through high quality neighborhood schools and engaged parents, and a solid physical infrastructure including high-quality housing in the neighborhood to support the community. The community looks to be on the right path toward stabilizing and empowering the Eastside to stay, grow, graduate and . . . stay.

To support all of the Promise Neighborhoods' efforts, HCZ, PolicyLink and the Center for the Study of Social Policy joined together to create the Promise Neighborhoods Institute at PolicyLink (PNI). Supported solely by private philanthropic dol-

lars, PNI provides communities with a system of support, resources, and information to help them in local Promise Neighborhoods efforts. PNI is already supporting 38 Promise Neighborhoods—including 21 funded by the U.S. Department of Education. PNI has three goals:

- Ensure the 21 Federal planning grantees are successful and transition to implementation.
- Support an additional 17 communities in their planning efforts and transition to implementation.
- Foster a national learning network that enable communities to learn from their peers and leverage resources in order to significantly improve the educational and developmental outcomes of children and youth in the Nation's most distressed communities.

To accomplish these goals, PNI offers:

- Site visits designed to assess community need and implement a comprehensive and personalized package of technical assistance services that help communities learn, make systemic, organizational and programmatic improvements and achieve measurable and sustainable results.
- Promise Neighborhood Network conferences to share best practices.
- Trainings on topics such as how to attract funding and talk to the media.
- Webinars and discussions moderated by experts in the field.
- A website—PromiseNeighborhoodsInstitute.org—featuring in-depth resources and tools.

Since its launch, PNI has:

- Developed a rich menu of technical assistance that is based on what works.
- Grown a robust community of practice that is being accessed by more than 2,000 people.
- Implemented a feedback loop to continually refine city, county, State, and Federal public policy and philanthropic approaches.
- Mobilized neighborhood leaders to advocate for integrated neighborhood revitalization investments to become the norm in solving some of the Nation's most intractable problems affecting poor children and families.

In the current planning phase, Promise Neighborhoods are getting ready to apply for full implementation. They are developing strategic business plans to estimate revenues and cover costs. Part of this includes the development of data systems for how they will track and evaluate data to make sure that they can document success, and catch and deal with challenges. In addition, they are developing powerful partnerships with schools and with organizations and agencies so they can provide children and families with the supports and services that are needed for success from cradle to college and career. We look forward to continuing to work with the Promise Neighborhoods grantees and others as they transition from planning to implementation. And, we look forward to seeing the results of their efforts.

We urge the Committee to support Promise Neighborhoods with resources for new sites to engage in planning, and for robust support for implementation in communities across the country. Thank you for your consideration. If you should need additional information about The Promise Neighborhoods program please contact Judith Bell from PolicyLink (Judith@policylink.org) or Katie Shoemaker at HCZ (kshoemaker@hcz.org).

PREPARED STATEMENT OF THE HEALTH PROFESSIONS AND NURSING EDUCATION
COALITION

The members of the Health Professions and Nursing Education Coalition (HPNEC) are pleased to submit this statement for the record in support of the fiscal year 2012 budget request of \$762.5 million for the health professions education programs authorized under Titles VII and VIII of the Public Health Service Act and administered through the Health Resources and Services Administration (HRSA). HPNEC is an informal alliance of more than 60 national organizations representing schools, programs, health professionals, and students dedicated to ensuring the healthcare workforce is trained to meet the needs of the country's growing, aging, and diverse population. For a complete list of HPNEC members, visit <http://www.aamc.org/advocacy/hpniec/members.htm>.

As you know, the Title VII and VIII health professions and nursing programs provide education and training opportunities to a wide variety of aspiring healthcare professionals, both preparing them for careers in the health professions and helping bring healthcare services to our rural and underserved communities. An essential component of the healthcare safety net, the Title VII and Title VIII programs are the only Federal programs designed to train healthcare providers in interdisciplinary

nary settings to meet the needs of the country's special and underserved populations, as well as increase minority representation in the healthcare workforce. Through loans, loan guarantees, and scholarships to students, and grants and contracts to academic institutions and nonprofit organizations, the Title VII and Title VIII programs fill the gaps in the supply of health professionals not met by traditional market forces.

Authorized since 1963, the Title VII and Title VIII education and training programs are designed to help the workforce adapt to the evolving healthcare needs of the ever-changing American population. In an effort to renew and update Titles VII and VIII to meet current workforce challenges, the programs were reauthorized in 2010—the first reauthorization in the past decade. Reauthorization not only improved the efficiency of the Title VII and Title VIII programs, but also laid the groundwork for innovative programs with an increased focus on recruiting and retaining professionals in underserved communities.

HPNEC is grateful for the Subcommittee's longstanding support of these important workforce programs. While we are keenly aware that the Subcommittee continues to face difficult decisions as it seeks to improve the Nation's fiscal health, a continued congressional commitment to programs supporting healthcare workforce development is essential to the physical health and prosperity of the American people. The country faces a critical disparity between the supply of practicing healthcare providers and the increasing demand for care, with HRSA estimating that over 33,000 additional health practitioners are needed to alleviate existing shortages. Destabilizing funding for the Title VII and Title VIII programs would reduce education and training support for primary care physicians, nurses, and other health professionals, exacerbating shortages and further straining the Nation's already fragile healthcare system. We recognize that relative to other Federal programs, HRSA's fiscal year 2011 operating plan imposes modest cuts to most Title VII and Title VIII programs, and we look forward to working with the subcommittee to prevent any further erosion to Federal support for health professions training.

Failure to fully fund the programs would jeopardize activities to train professionals across all disciplines to coordinate care for the Nation's expanding elderly population; limit training opportunities for providers to meet the unique needs of the Nation's sick and ailing children; severely impact the distribution of professionals practicing in rural and underserved communities; and hinder efforts to recruit and retain a diverse and culturally competent workforce. To ensure the healthcare workforce is equipped to address these issues, a strong commitment to the Title VII and Title VIII programs is essential.

The existing Title VII and Title VIII programs can be considered in seven general categories:

- The Primary Care Medicine and Oral Health Training programs, now authorized separately, provide for the education and training of primary care physicians, physician assistants, and dentists, to improve access and quality of healthcare in underserved areas. Two-thirds of all Americans interact with a primary care provider every year. Approximately one-half of primary care providers trained through these programs go on to work in underserved areas, compared to 10 percent of those not trained through these programs. The General Pediatrics, General Internal Medicine, and Family Medicine programs provide critical funding for primary care training in community-based settings and have been successful in directing more primary care physicians to work in underserved areas. They support a range of initiatives, including medical student training, residency training, faculty development and the development of academic administrative units. These programs also enhance the efforts of osteopathic medical schools to continue to emphasize primary care medicine, health promotion, and disease prevention, and the practice of ambulatory medicine in community-based settings. Recognizing that all primary care is not only provided by physicians, the primary care cluster also provides grants for Physician Assistant programs to encourage and prepare students for primary care practice in rural and urban Health Professional Shortage Areas. The General Dentistry, Pediatric Dentistry, and Public Health Dentistry programs provide grants to dental schools and hospitals to create or expand primary care and public health dental residency training programs.
- Because much of the Nation's healthcare is delivered in areas far removed from health professions schools, the Interdisciplinary, Community-Based Linkages cluster provides support for community-based training of various health professionals. These programs are designed to provide greater flexibility in training and to encourage collaboration between two or more disciplines. These training programs also serve to encourage health professionals to return to such settings after completing their training. The Area Health Education Centers (AHECs)

provide clinical training opportunities to health professions and nursing students in rural and other underserved communities by extending the resources of academic health centers to these areas. AHECs, which have substantial State and local matching funds, form networks of health-related institutions to provide education services to students, faculty and practitioners. Geriatric Health Professions programs support geriatric faculty fellowships, the Geriatric Academic Career Award, and Geriatric Education Centers, which are all designed to bolster the number and quality of healthcare providers caring for our older generations. Given America's burgeoning aging population, there is a need for specialized training in the diagnosis, treatment, and prevention of disease and other health concerns of older adults. The Mental and Behavioral Health Education and Training Programs help mitigate the growing shortages of mental and behavioral health providers by providing grants for training social workers, child and adolescent mental health professionals, and paraprofessionals working with children and adolescents. They also provide grants to doctoral, internship, and postdoctoral programs through the Graduate Psychology Education program, which supports interdisciplinary training of psychology students with other health professionals for the provision of mental and behavioral health services to underserved populations (i.e., older adults, children, chronically ill, and victims of abuse and trauma, including returning military personnel and their families), especially in rural and urban communities.

- The purpose of the Minority and Disadvantaged Health Professions Training programs is to improve healthcare access in underserved areas and the representation of minority and disadvantaged healthcare providers in the health professions. Minority Centers of Excellence support programs that seek to increase the number of minority health professionals through increased research on minority health issues, establishment of an educational pipeline, and the provision of clinical opportunities in community-based health facilities. The Health Careers Opportunity Program seeks to improve the development of a competitive applicant pool through partnerships with local educational and community organizations. The Faculty Loan Repayment and Faculty Fellowship programs provide incentives for schools to recruit underrepresented minority faculty. The Scholarships for Disadvantaged Students make funds available to eligible students from disadvantaged backgrounds who are enrolled as full-time health professions students.
- The Health Professions Workforce Information and Analysis program provides grants to institutions to collect and analyze data on the health professions workforce to advise future decisionmaking on the direction of health professions and nursing programs. The Health Professions Research and Health Professions Data programs have developed a number of valuable, policy-relevant studies on the distribution and training of health professionals, including the Eighth National Sample Survey of Registered Nurses, the Nation's most extensive and comprehensive source of statistics on registered nurses. In conjunction with the reauthorization of the Title VII programs and in recognition of the need for better health workforce data to inform both public and private decisionmaking, the National Center for Workforce Analysis serves as a source of data and information on the health workforce for the Nation.
- The Public Health Workforce Development programs are designed to increase the number of individuals trained in public health, to identify the causes of health problems, and respond to such issues as managed care, new disease strains, food supply, and bioterrorism. The Public Health Traineeships and Public Health Training Centers seek to alleviate the critical shortage of public health professionals by providing up-to-date training for current and future public health workers, particularly in underserved areas. Preventive Medicine Residencies, which receive minimal funding through Medicare GME, provide training in the only medical specialty that teaches both clinical and population medicine to improve community health. The Title VII reauthorization reorganized this cluster to include a focus on loan repayment as an incentive for health professionals to practice in disciplines and settings experiencing shortages. The Pediatric Subspecialty Loan Repayment Program offers loan repayment for pediatric medical subspecialists, pediatric surgical specialists, and child and adolescent mental and behavioral health specialists, in exchange for services in areas where these types of professionals are in short supply. The Public Health Workforce Loan Repayment Program provides loan repayment for public health professionals accepting employment with Federal, State, local, and tribal public health agencies.
- The Nursing Workforce Development programs under Title VIII provide training for entry-level and advanced degree nurses to improve the access to, and

quality of, healthcare in underserved areas. These programs provide the largest source of Federal funding for nursing education, providing loans, scholarships, traineeships, and programmatic support that, between fiscal year 2006 and 2009, supported over 347,000 nurses and nursing students as well as numerous academic nursing institutions, and healthcare facilities. Healthcare entities across the Nation are experiencing a crisis in nurse staffing, caused in part by an aging workforce and capacity limitations within the educational system. Each year, nursing schools turn away tens of thousands of qualified applications at all degree levels due to an insufficient number of faculty, clinical sites, classroom space, clinical preceptors, and budget constraints. At the same time, the need for nursing services and licensed, registered nurses is expected to increase significantly over the next 20 years. The Advanced Education Nursing program awards grants to train a variety of advanced practice nurses, including nurse practitioners, certified nurse-midwives, nurse anesthetists, public health nurses, nurse educators, and nurse administrators. Workforce Diversity grants support opportunities for nursing education for students from disadvantaged backgrounds through scholarships, stipends, and retention activities. Nurse Education, Practice, and Retention grants are awarded to help schools of nursing, academic health centers, nurse-managed health centers, State and local governments, and other healthcare facilities to develop programs that provide nursing education, promote best practices, and enhance nurse retention. The Loan Repayment and Scholarship Program repays up to 85 percent of nursing student loans and offers full-time and part-time nursing students the opportunity to apply for scholarship funds. In return these students are required to work for at least 2 years of practice in a designated nursing shortage area. The Comprehensive Geriatric Education grants are used to train RNs who will provide direct care to older Americans, develop and disseminate geriatric curriculum, train faculty members, and provide continuing education. The Nurse Faculty Loan program provides a student loan fund administered by schools of nursing to increase the number of qualified nurse faculty.

—The loan programs under Student Financial Assistance support financially needy and disadvantaged medical and nursing school students in covering the costs of their education. The Nursing Student Loan (NSL) program provides loans to undergraduate and graduate nursing students with a preference for those with the greatest financial need. The Primary Care Loan (PCL) program provides loans covering the cost of attendance in return for dedicated service in primary care. The Health Professional Student Loan (HPSL) program provides loans covering the cost of attendance for financially needy health professions students based on institutional determination. The NSL, PCL, and HPSL programs are funded out of each institution's revolving fund and do not receive Federal appropriations. The Loans for Disadvantaged Students program provides grants to health professions institutions to make loans to health professions students from disadvantaged backgrounds.

By improving the supply, distribution, and diversity of the Nation's healthcare professionals, the Title VII and Title VIII programs not only prepare aspiring professionals to meet the country's workforce needs, but also help to improve access to care across all populations. The multi-year nature of health professions education and training, coupled with unprecedented existing and looming provider shortages across many disciplines and in many communities, necessitate a strong, continued, and reliable commitment to the Title VII and Title VIII programs.

While HPNEC members understand of the immense fiscal pressures facing the Subcommittee, we respectfully urge support for \$762.5 million for the Title VII and VIII programs, a commitment essential not only to the development and training of tomorrow's healthcare professionals but also to our Nation's efforts to provide needed healthcare services to underserved communities. We forward to working with Senators to prioritize the health professions programs in fiscal year 2012 and into the future.

PREPARED STATEMENT OF THE HEPATITIS B FOUNDATION

Highlighting the urgent need to address the public health challenges of chronic hepatitis B by strengthening programs at the Centers for Disease Control and Prevention, and the National Institutes of Health.

Mr. Chairman, my name is Dr. Timothy Block, and I am the President and Co-Founder of the Hepatitis B Foundation and its research institute, the Institute for Hepatitis and Virus Research. I also serve as the President of the Pennsylvania Biotechnology Center and am a professor at Drexel University College of Medicine. My

wife Joan, and I, and another couple, Paul and Janine Witte, from Pennsylvania started the Hepatitis B Foundation 20 years ago to find a cure for this serious chronic liver disease and provide information and support to those affected.

Thank you for giving the Hepatitis B Foundation (HBF) the opportunity to provide testimony to the Subcommittee as you begin to consider funding priorities for fiscal year 2012. We are grateful to the Members of this Subcommittee for their interest and strong leadership for efforts to control and find cures for hepatitis B.

Today, the HBF is the only national nonprofit organization solely dedicated to finding a cure and improving the lives of those affected by hepatitis B worldwide through research, education and patient advocacy. Our scientists focus on drug discovery for hepatitis B and liver cancer, and early detection markers for liver cancer. HBF staff manages a comprehensive website which receives almost 1 million visitors each year, a national patient conference and outreach services. HBF public health professionals conduct research initiatives to advance our mission.

The hepatitis B virus (HBV) is the world's major cause of liver cancer—and while other cancers are declining, liver cancer is the fastest growing in incidence in the United States. Without intervention, as many as 100 million worldwide will die from a HBV-related liver disease, most notably liver cancer. In the United States, up to 2 million Americans have been chronically infected and more than 5,000 people die each year from complications due to HBV.

HBV is 100 times more infectious than the HIV/AIDS virus. Yet, hepatitis B can be prevented with a safe and effective vaccine. Unfortunately, for those who are chronically infected with HBV, the vaccine is too late. There are, however, promising new treatments for HBV. We are getting close to solutions but lack of sustained support for public health measures and scientific research is threatening progress. New research has confirmed that early detection and treatment significantly reduces healthcare costs, morbidity and mortality. The growing incidence of liver cancer, while most other cancer rates are on the decline, represents examples of serious shortcomings in our system. In the United States, 20,000 babies are born to mothers infected with HBV each year, and as many as 1,200 newborns will be chronically infected with the hepatitis B virus. More needs to be done to prevent new infections.

HHS Interagency Working Group on Viral Hepatitis

Last year, the Department of Health and Human Services put together an Interagency Working Group on Hepatitis to put together an Action Plan on Viral Hepatitis. This action plan will describe opportunities for HHS to respond to the 2010 Institute of Medicine (IOM) review of the viral hepatitis challenge in the United States and the IOM recommendations to prevent and build the capacity and collaborations essential for reducing the number of viral hepatitis infections and ameliorating the health and economic consequences of viral hepatitis among persons chronically infected. The Hepatitis B Foundation is very supportive of the efforts of the Working Group and is hopeful that its recommendations will result in actions to address the chronic underfunding of viral hepatitis prevention, research and outreach programs within the Department. We look forward to the release of the Hepatitis Action Plan in May of this year.

Mr. Chairman, as you know the two Federal agencies that are critical to the effort to help people concerned with hepatitis B are: the Centers for Disease Control and Prevention (CDC), and the National Institutes of Health (NIH).

The Centers for Disease Control

CDC's Division of Viral Hepatitis (DVH), the centerpiece of the Federal response to controlling, reducing and preventing the suffering and deaths resulting from viral hepatitis, is chronically underfunded. DVH is included in the National Center for HIV/AIDS, Viral Hepatitis, STD, and TB Prevention at the CDC, and is responsible for the prevention and control of viral hepatitis. DVH is currently (prior to finalization of the fiscal year 2011 continuing resolution) funded at \$19.8 million, approximately \$6 million less than its funding level in fiscal year 2003. In the President's fiscal year 2012 budget proposal, DVH is funded at \$25 million, an increase of \$5.2 million. The HBF is very supportive of this increase and joins the hepatitis community in urging the Committee to fund the President's request for the Division of Viral Hepatitis.

The responsibility for addressing the problem of hepatitis should not lie solely with the Division. In view of the preventable nature of these diseases, the Hepatitis B Foundation feels that the National Center for Chronic Disease Prevention should also include a targeted effort focused on the prevention of chronic viral hepatitis which adversely impacts 5 million Americans. Specifically, we ask that the Committee include language urging the Center to help insure that the Prevention and

Public Health Funds, particularly the Community Transformations Grants, are available to support viral hepatitis prevention projects.

Furthermore, there are 400 million people chronically infected with hepatitis B worldwide, with more than 120 million of these individuals in China. While hepatitis B transmission requires direct exposure to infected blood, worldwide misinformation about the disease has fueled inappropriate discrimination against individuals with this vaccine-preventable and treatable bloodborne disease. HBF urges the Committee to instruct the CDC to initiate global programs to increase the rate of vaccination, reduce mother-child transmission and promote educational programs to prevent the disease and to reduce discrimination targeted against individuals with the disease.

The National Institutes of Health

We depend upon the NIH to fund research that will lead to new and more effective interventions to treat people with hepatitis B and liver cancer. The Hepatitis B Foundation joins with the Ad Hoc Group for Biomedical Research and requests a funding level of \$35 billion for the National Institutes of Health in fiscal year 2012.

We thank the Committee for their continued investment in the NIH. Sustaining progress in medical research is essential to the twin national priorities of smarter healthcare and economic revitalization. With additional investment, the Nation can seize the unique opportunity to build on the tremendous momentum emerging from the strategic investment in NIH made through the 2009 American Recovery and Reinvestment Act (ARRA). NIH invested those funds in a range of potentially revolutionary new avenues of research that will lead to new early screenings and new treatments for disease.

In fiscal year 2010, NIH spent approximately \$70 million on hepatitis B funding overall including \$4 million of onetime funding from the American Recovery and Reinvestment Act. It is estimated that in fiscal year 2011 hepatitis B funding will return to the base level of \$66 million. Additional funding could make transformational advances in research leading to better treatments for HBV. The Hepatitis B Foundation recommends that at a minimum, funding allocated for HBV research in fiscal year 2012 be increased at the same rate recommended for NIH overall and, therefore, funded at \$75.7 million.

The current leadership of the NIH has performed admirably with the limited resources they are provided; however, more is needed. While a number of cancers have achieved 5-year survival rates of over 80 percent and the average 5-year survival rate for all cancers has increased from 50 percent in 1971 to 66 percent, significant challenges still remain for other types of cancers, particularly the most deadly forms of cancer. In fact, nearly half of the 562,340 cancer deaths in 2009 were caused by eight forms of cancer with 5-year relative survival rates of less than 50 percent: ovary (45.5 percent), brain (35.0 percent), myeloma (34.9 percent), stomach (24.7 percent), esophagus (15.8 percent), lung (15.2 percent), liver (11.7 percent), and pancreas (5.1 percent). It is no coincidence that cancers with significantly better 5 year survival rates, such as breast, prostate, colon, testicular, and chronic myelogenous leukemia, also have early detection tools, and in many cases, several effective treatment options thanks to research programs championed and supported by Congress. By contrast, research into the cancers with the lowest 5-year survival rates has been relatively under-funded, and as a result, these cancers have no early detection or treatment tools.

The Hepatitis B Foundation requests the establishment of a targeted cancers program at the National Cancer Institute (NCI) for the high mortality cancers. It should include a strategic plan for progress, an annual report from NCI to Congress, and a new grant program specifically focused on the deadly cancers. Additionally, the Hepatitis B Foundation urges a stronger focus on liver cancer and urges the funding of a series of Specialized Programs of Research Excellence (SPORes) focused on liver cancer. While SPORes currently exist for every other major cancer, none currently exist that are focused on liver cancer.

Prevention Fund

The Patient Protection and Affordable Care Act included the creation of a Prevention and Public Health Fund, to be used to reduce chronic disease rates and to address health disparities. To further clarify the intended use of these funds, earlier this year, the National Prevention, Health Promotion and Public Health Council that was established to advise on the use of these funds, released a report with recommendations. Included in the report were recommendations that "opportunities be expanded within communities and populations at greatest risk for diseases such as Viral Hepatitis B and C" and that there be an increased use of the "the most effective

tive and highest impact evidence-based clinical preventive services and medications, such as screening and treatment for chronic viral hepatitis.” Therefore, it is our view that insuring the Prevention Funds resources can be used for viral hepatitis prevention projects would help address this urgent need to help close the gap between diagnosis and access to care for hepatitis patients. We urge the Committee to include language in both the Office of the Secretary and the CDC’s National Center for Chronic Disease Prevention to insure that Prevention Funds, specifically Community Transformation Grants, be eligible to viral hepatitis initiatives.

SUMMARY AND CONCLUSION

While the HBF recognizes the demands on our Nation’s resources, we believe the ever-increasing health threats and expanding scientific opportunities continue to justify higher funding levels for the CDC’s Division of Viral Hepatitis and the National Institutes of Health.

Significant progress has been made in developing better treatments and cures for the diseases that affect humankind due to your leadership and the leadership of your colleagues on this Subcommittee. Significant progress has also similarly been made in the fight against hepatitis B.

In conclusion, we specifically request the following for fiscal year 2012:

- Fund the CDC’s Division of Viral Hepatitis at \$25 million;
- Language urging the HHS and the National Center for Chronic Disease Prevention to help insure that the Prevention and Public Health Funds, particularly the Community Transformations Grants, are available to support viral hepatitis prevention projects.
- Initiate global programs at the CDC to increase the rate of vaccination, reduce mother-child transmission and promote educational programs to prevent the disease and to reduce discrimination targeted against individuals with the disease;
- Provide \$35 billion for the National Institutes of Health, including a \$9.7 million increase per year for hepatitis B research;
- Establish a targeted cancers program at the NCI; and
- Fund a series of Specialized Programs of Research Excellence (SPORes) focused on liver cancer at the NCI.

The Hepatitis B Foundation appreciates the opportunity to provide testimony to you on behalf of our constituents and yours.

PREPARED STATEMENT OF THE HIV MEDICINE ASSOCIATION

The HIV Medicine Association (HIVMA) of the Infectious Diseases Society of America (IDSA) represents more than 4,500 physicians, scientists and other healthcare professionals who practice on the frontline of the HIV/AIDS pandemic. Our members provide medical care and treatment to people with HIV/AIDS throughout the United States, lead HIV prevention programs and conduct research to develop effective HIV prevention and treatment options. We work in communities across the country and around the globe as medical providers and researchers dedicated to the field of HIV medicine.

We appreciate the importance of addressing the fiscal challenges facing our Nation, but the continued fragile state of the economy makes it imperative to set priorities to ensure that our Nation has a strong healthcare safety-net, effective programs for preventing infectious diseases like HIV and a robust scientific research agenda.

The U.S. investment in HIV/AIDS programs has revolutionized HIV care globally, making HIV treatment one of the most effective medical interventions available. A vibrant research agenda and rapid public health implementation of scientific findings have transformed the HIV epidemic, reducing morbidity and mortality due to HIV disease by nearly 80 percent in the United States.

Implementation of healthcare reform and the administration’s plans for a National HIV/AIDS Strategy offer promise for making significant progress in reducing the impact of the domestic HIV epidemic. However, their success will depend on maintaining adequate investments in the healthcare safety net, and in prevention, public health and research programs. The funding requests in our testimony largely reflect the consensus of the Federal AIDS Policy Partnership (FAPP), a coalition of HIV organizations from across the country, and are estimated to be the amounts necessary to sustain and strengthen our investment in combatting HIV disease.

Health Care Reform

We urge full funding of the President's fiscal year 2012 request level for healthcare reform programs supported with discretionary funding under the Patient Protection and Affordable Care Act (ACA), in particular: health workforce education and training programs under Titles VII and VIII of the Public Health Service Act (PHSA); healthcare quality improvement programs, and the Community Health Centers program.

HIV/AIDS Bureau of the Health Resources and Services Administration

We urge you to increase funding for the Ryan White program by \$371 million in fiscal year 2011 with at least an increase of \$65.8 million over the fiscal year 2010 level for Part C. At minimum, we strongly urge you to support the President's proposed fiscal year 2012 increase of \$88.3 million for the Ryan White program, including a \$5.1 million increase for Part C. Part C of the Ryan White Program funds comprehensive HIV care and treatment—services that are directly responsible for the dramatic decreases in AIDS-related mortality and morbidity over the last decade. On average it costs \$3,501 per person per year to provide the comprehensive outpatient care and treatment available at Part C funded programs, including lab work, STD/TB/Hepatitis screening, ob/gyn care, dental care, mental health and substance abuse treatment, and case management. Part C funding covers a small percentage of the total cost of providing comprehensive care with some programs receiving \$450 or lower per patient per year to cover care.

The Ryan White Program generally is underfunded and Part C of the program is disproportionately and severely underfunded. The Centers for Disease Control and Prevention estimate that there are more than 1.1 million persons living with HIV/AIDS and approximately 240,000, or almost 1 in 4, of these individuals receive services from Part C medical providers. Of the 240,000 patients, approximately 1 out of 3 is uninsured, and 2 out of 3 are underinsured.

While the patient caseload in Part C programs has been rising, funding for Part C has effectively decreased due to flat funding and funding cuts at the clinic level. Part C programs expect a continued increase in patients due to higher diagnosis rates and economic-related declines in insurance coverage. During this economic downturn people with HIV across the country are relying on Part C comprehensive services more than ever. As a result of consistently increasing caseloads and limited funding, Part C clinics are taking dramatic steps that adversely impact their ability to serve patients, including: Limiting primary care services; discontinuing critical services such as laboratory monitoring; suffering eviction from institutional-based clinic sites; laying off staff; and operating only 4 days/week.

The HIV medical clinics funded through Part C have been in dire need of increased funding for years, but new pressures are creating a crisis in communities across the country. An increase in funding is critical to prevent additional staffing and service cuts and ensure the public health of our communities.

National Institutes of Health (NIH)—Office of AIDS Research

HIVMA supports the medical research community's requested increase of \$4 billion over the fiscal year 2010 level for all research programs at the NIH, including at least a \$400 million increase for the NIH Office of AIDS. This level of funding is vital to sustain the pace of research that will improve the health and quality of life for millions of Americans. At minimum, we urge you to support the President's proposed fiscal year 2012 increase of \$1 billion for the NIH.

A continued robust AIDS research portfolio is essential to sustain and to accelerate our progress in offering more effective prevention technologies; developing new and less toxic therapy; and supporting the basic research necessary to continue our work developing a vaccine that may end the deadliest pandemic in human history.

We appreciate the many difficult decisions that Congress faces this year, but urge you to recognize the importance of investing in HIV prevention, treatment and research now to avoid the much higher cost that individuals, communities and broader society will incur if we fail to support these programs. We must seize the opportunity to limit the toll of this deadly infectious disease on our planet and to save the lives of millions who are infected or at risk of infection here in the United States and around the globe.

Center for Disease Control and Prevention's (CDC) National Center for HIV/AIDS, Viral Hepatitis, STD, and TB Prevention (NCHHSTP)

HIVMA strongly urges total fiscal year 2012 funding of \$1.953 billion for the CDC's NCHHSTP, an increase of \$834.1 million over the fiscal year 2010 level, including increases of: \$515.3 million for HIV prevention and surveillance, \$20.2 million for viral hepatitis and \$85.9 million for tuberculosis prevention.

Every 9½ minutes a new HIV infection happens in the United States with more than 60 percent of new cases occurring among African Americans and Hispanic/Latinos. Despite the known benefit of effective treatment, 21 percent of people living with HIV in the United States are still not aware of their status and as many as 36 percent of people newly diagnosed with HIV progress to AIDS within 1 year of diagnosis. A sustained commitment to HIV prevention funding is critical to enhance HIV/AIDS surveillance and expand HIV testing and linkage to care, in order to lower HIV incidence and prevalence in the United States. We appreciate that the President proposed a \$68.8 million increase for HIV prevention at the CDC, and at a bare minimum we strongly urge the Committee to at least meet this request.

Finally, we strongly support adequate funding for science-based, comprehensive sex education programs. We are pleased that the fiscal year 2011 continuing resolution provides \$109 million for the Teen Pregnancy Prevention Program, which focuses on reducing the risks of pregnancy and sexually transmitted diseases through proven and successful models. We urge the Committee to adopt report language supporting true, comprehensive sex education that promotes healthy behaviors and relationships for all young people, including lesbian, gay, bisexual, and transgender youth, including an explicit focus on prevention of HIV and other STDs.

CDC—Tuberculosis

Tuberculosis is the major cause of AIDS-related mortality worldwide and the second leading infectious disease killer. Congress passed landmark legislation in the Comprehensive Tuberculosis Elimination Act of 2008 to shore up State TB control programs, to enhance U.S. capacity to address drug-resistant tuberculosis; and to develop new drugs, diagnostics and vaccines.

State budget cuts have hit local TB control programs hard, and the CDC Division of TB Elimination has seen some budget reductions in the last 2 fiscal years. Our ability to respond to TB within our own borders is being compromised as a result. We must do better. Finally, we are beginning to see exciting new tools to combat tuberculosis after decades of little or no productive research and development in this area. We have an exciting new diagnostic test that can identify drug-susceptible and drug-resistant TB very quickly. There are a number of new drugs in clinical trials for both drug resistant and drug-susceptible TB. There are promising new TB vaccine candidates being tested. Now, resources are needed more urgently than ever to follow through on the research and development in progress and to ensure that these new tools reach the public health officials on the ground who need them. We respectfully request fiscal year 2012 funding for the CDC Division of TB Elimination at a level of \$231 million. At minimum, we urge full funding of the President's fiscal year 2012 budget request of \$143.6 million for this program.

CDC—Viral Hepatitis

A much more substantial commitment to Hepatitis co-infection is urgently needed, in addition to funding for core public health services and tracking of chronic cases of hepatitis. Co-infection is a serious health threat for nearly one-third of our HIV patients, and has an enormous impact on morbidity and mortality. Furthermore, with the advent of the recently approved protease inhibitors, providing funding to enable this population to receive treatment and/or access clinical trials becomes absolutely critical. We strongly urge you to boost funding for viral hepatitis at the CDC by \$20.2 million over the fiscal year 2010 level million for a total funding of \$40 million. At the very least, we urge you to support the President's proposed fiscal year 2012 increase of \$5.2 million to respond to the viral Hepatitis epidemic.

Agency for Health Care Quality and Research (AHRQ)

HIVMA urges the Committee to provide \$2.2 million, a \$200,000 increase over the fiscal year 2010 level for the HIV Research Network (HIVRN), the only significant HIV work being done at AHRQ. The HIVRN is a consortium of 18 HIV primary care sites co-funded by AHRQ and HRSA to evaluate healthcare utilization and clinical outcomes in HIV infected children, adolescents and adults in the United States. The Network analyzes and disseminates information on the delivery and outcomes of healthcare services to people with HIV infection. These data help to improve delivery and outcomes of HIV care in the United States and to identify and address disparities in HIV care that exist by race, gender, and HIV risk factor. The HIVRN is a unique source of information on the cost and cost-effectiveness of HIV care in the United States at a time when data on comparative cost and effectiveness of healthcare is particularly needed to inform health systems reform and the development and implementation of a National HIV/AIDS Strategy.

PREPARED STATEMENT OF HOWARD UNIVERSITY

Mr. Chairman and members of the subcommittee, thank you for the opportunity to present my views before you today. I am Dr. Eve Higginbotham, Senior Vice-President and Executive Dean for Howard University Health Sciences. I am the senior health official at Howard, with responsibilities for our College of Medicine, College of Dentistry, College of Pharmacy, Nursing, and Allied Health, Louis Stokes Health Sciences Library, and the Howard University Hospital. Howard University is the only Historically Black College or University (HBCU) with so many aspects of the health sciences housed at one institution. For that reason, we are poised to continue to impact the education of minorities and others dedicated to improving the health of all Americans.

Mr. Chairman, Howard University Health Sciences has made historic contributions to the reduction of health disparities, and it is because of programmatic activity like the Title VII Health Professions Training programs that we are able to address a critical national need. Persistent and severe staffing shortages exist in a number of the health professions, and chronic shortages exist for all of the health professions in our Nation's most medically underserved communities. Furthermore, even after the landmark passage of health reform, it is important to note that our Nation's health professions workforce does not accurately reflect the racial composition of our population. For example while blacks represent approximately 15 percent of the U.S. population, only 2–3 percent of the Nation's health professions workforce is black. Mr. Chairman, I would like to share with you how your committee can help HUHS continue our efforts to help provide quality health professionals and close our Nation's health disparity gap.

There is a well established link between health disparities and a lack of access to competent healthcare in medically underserved areas. As a result, it is imperative that the Federal Government continue its commitment to minority health professions institutions and minority health professional training programs to continue to produce healthcare professionals committed to addressing this unmet need—even in austere financial times.

An October 2006 study by the Health Resources and Services Administration (HRSA), entitled "The Rationale for Diversity in the Health Professions: A Review of the Evidence" found that minority health professionals serve minority and other medically underserved populations at higher rates than non-minority professionals. The report also showed that; minority populations tend to receive better care from practitioners who represent their own race or ethnicity, and non-English speaking patients experience better care, greater comprehension, and greater likelihood of keeping follow-up appointments when they see a practitioner who speaks their language. Studies have also demonstrated that when minorities are trained in minority health profession institutions, they are significantly more likely to: (1) serve in rural and urban medically underserved areas, (2) provide care for minorities and (3) treat low-income patients.

As you are aware, Title VII Health Professions Training programs are focused on improving the quality, geographic distribution and diversity of the healthcare workforce in order to continue eliminating disparities in our Nation's healthcare system. These programs provide training for students to practice in underserved areas, cultivate interactions with faculty role models who serve in underserved areas, and provide placement and recruitment services to encourage students to work in these areas. Health professionals who spend part of their training providing care for the underserved are up to 10 times more likely to practice in underserved areas after graduation or program completion.

In fiscal year 2012, funding for the Title VII Health Professions Training programs must at the very least be maintained, especially the funding for the Minority Centers of Excellence (COEs) and Health Careers Opportunity Program (HCOPs). In addition, the funding for the National Institutes of Health (NIH)'s National Institute on Minority Health and Health Disparities (NIMHD), as well as the Department of Health and Human Services (HHS)'s Office of Minority Health (OMH), should be preserved.

Minority Centers of Excellence.—COEs focus on improving student recruitment and performance, improving curricula in cultural competence, facilitating research on minority health issues and training students to provide health services to minority individuals. COEs were first established in recognition of the contribution made by four historically black health professions institutions to the training of minorities in the health professions. Congress later went on to authorize the establishment of "Hispanic", "Native American" and "Other" Historically black COEs. For fiscal year 2012, I recommend a funding level of \$24.602 million for COEs.

Health Careers Opportunity Program (HCOP).—HCOPs provide grants for minority and non-minority health profession institutions to support pipeline, preparatory and recruiting activities that encourage minority and economically disadvantaged students to pursue careers in the health professions. Many HCOPs partner with colleges, high schools, and even elementary schools in order to identify and nurture promising students who demonstrate that they have the talent and potential to become a health professional. For fiscal year 2012, I recommend a funding level of \$22.133 million for HCOPs.

National Institutes of Health

Research Centers at Minority Institutions.—The Research Centers at Minority Institutions program (RCMI), currently administered by the National Center for Research Resources, has a long and distinguished record of helping our institutions develop the research infrastructure necessary to be leaders in the area of health disparities research. Although NIH has received unprecedented budget increases in recent years, funding for the RCMI program has not increased by the same rate. Therefore, the funding for this important program grow at the same rate as NIH overall in fiscal year 2012.

National Institute on Minority Health and Health Disparities.—The National Institute on Minority Health and Health Disparities (NIMHD) is charged with addressing the longstanding health status gap between minority and nonminority populations. The NIMHD helps health professions institutions to narrow the health status gap by improving research capabilities through the continued development of faculty, labs, and other learning resources. The NIMHD also supports biomedical research focused on eliminating health disparities and develops a comprehensive plan for research on minority health at the NIH. Furthermore, the NIMHD provides financial support to health professions institutions that have a history and mission of serving minority and medically underserved communities through the Centers of Excellence program. For fiscal year 2012, I recommend funded increases proportional with the funding of the over NIH.

Department of Health and Human Services

Department of Health and Human Services' Office of Minority Health.—Specific programs at OMH include: assisting medically underserved communities with the greatest need in solving health disparities and attracting and retaining health professionals; assisting minority institutions in acquiring real property to expand their campuses and increase their capacity to train minorities for medical careers; supporting conferences for high school and undergraduate students to interest them in health careers, and supporting cooperative agreements with minority institutions for the purpose of strengthening their capacity to train more minorities in the health professions. The OMH has the potential to play a critical role in addressing health disparities. For fiscal year 2012, I recommend a funding level of \$65 million for the OMH.

Department of Education

Howard University Academic, Research, and Hospital Support.—The Department of Education maintains support for Howard University's academic programs, research programs, construction activities, and the Howard University Hospital. Howard University has played a historic role in providing access to postsecondary educational opportunities for students from traditionally underrepresented backgrounds, especially African Americans. For this reason, and others, Howard is supported annually with a Federal appropriation. The direct Federal appropriation accounts for approximately 50 percent of the Howard University's operating costs, including nearly \$29 million for the operation of the Howard Hospital—a staple of care for residents in Northwest Washington, DC. In fiscal year 2012, an appropriation of \$235 million is suggested to continue the vital programs and services which we provide.

Mr. Chairman, please allow me to express my appreciation to you and the members of this subcommittee. With your continued help and support, Howard University's Health Sciences can help this country to overcome health disparities. Congress must be careful not to eliminate, paralyze or stifle programs that have been proven to work. HUHS seeks to close the ever widening health disparity gap. If this subcommittee will give us the tools, we will continue to work towards the goal of eliminating that disparity everyday.

Thank you, Mr. Chairman, and I welcome every opportunity to answer questions for your records.

PREPARED STATEMENT OF THE INTERNATIONAL FOUNDATION FOR FUNCTIONAL
GASTROINTESTINAL DISORDERS

Thank you for the opportunity to present the views of the International Foundation for Functional Gastrointestinal Disorders (IFFGD) regarding the importance of functional gastrointestinal (GI) and motility disorders research.

Established in 1991, IFFGD is a patient-driven nonprofit organization dedicated to assisting individuals affected by functional GI disorders, and providing education and support for patients, healthcare providers, and the public at large. The IFFGD also works to advance critical research on functional GI and motility disorders, in order to provide patients with better treatment options, and to eventually find a cure. IFFGD has worked closely with NIH on a number of priorities, including the NIH State-of-the-Science Conference on the Prevention of Fecal and Urinary Incontinence in Adults through NIDDK, the National Institute of Child Health and Human Development (NICHD), and the Office of Medical Applications of Research (OMAR). I have served on the National Commission on Digestive Diseases (NCDD), which released a long-range road map for digestive disease research in 2009, entitled *Opportunities and Challenges in Digestive Diseases Research: Recommendations of the National Commission on Digestive Diseases*.

The need for increased research, more effective and efficient treatments, and the hope for discovering a cure for functional GI and motility disorders are close to my heart. My own personal experiences of suffering from functional GI and motility disorders motivated me to establish IFFGD 20 years ago. I was shocked to discover that despite the high prevalence of these conditions among all demographic groups worldwide, such an appalling lack of dedicated research existed. This lack of research translates into a dearth of diagnostic tools, treatments, and patient supports. Even more shocking is the lack of awareness among both the medical community and the general public, leading to significant delays in diagnosis, frequent misdiagnosis, and inappropriate treatments including unnecessary medication and surgery. It is unacceptable for patients to suffer unnecessarily from the severe, painful, life-altering symptoms of functional GI and motility disorders due to a lack of awareness and education.

The majority of functional GI disorders have no cure and treatment options are limited. Although progress has been made, the medical community still does not completely understand the mechanisms of the underlying conditions. Without a known cause or cure, patients suffering from functional GI disorders face a lifetime of chronic disease management, learning to adapt to intolerable, disruptive symptoms. The medical and indirect costs associated with these diseases are enormous; estimates range from \$25–\$30 billion annually. Economic costs spill over into the workplace, and are reflected in work absenteeism and lost productivity. Furthermore, the emotional toll of these conditions affects not only the individual but also the family. Functional GI disorders do not discriminate, affecting all ages, races and ethnicities, and genders.

Irritable Bowel Syndrome (IBS)

IBS, one of the most common functional GI disorders, strikes all demographic groups. It affects 30 to 45 million Americans, conservatively at least 1 out of every 10 people. Between 9 to 23 percent of the worldwide population suffers from IBS, resulting in significant human suffering and disability. IBS as a chronic disease is characterized by a group of symptoms that may vary from person to person, but typically include abdominal pain and discomfort associated with a change in bowel pattern, such as diarrhea and/or constipation. As a “functional disorder”, IBS affects the way the muscles and nerves work, but the bowel does not appear to be damaged on medical tests. Without a definitive diagnostic test, many cases of IBS go undiagnosed or misdiagnosed for years. It is not uncommon for IBS sufferers to have unnecessary surgery, medication, and medical devices before receiving a proper diagnosis. Even after IBS is identified, treatment options are sorely lacking and vary widely from patient to patient. What is known is that IBS requires a multidisciplinary approach to research and treatment.

IBS can be emotionally and physically debilitating. Due to persistent pain and bowel unpredictability, individuals who suffer from this disorder may distance themselves from social events, work, and even may fear leaving their home. Stigma surrounding bowel habits may act as barrier to treatment, as patients are not comfortable discussing their symptoms with doctors. Because IBS symptoms are relatively common and not life-threatening, many people dismiss their symptoms or attempt to self-medicate using over-the-counter medications. In order to overcome these barriers to treatment, ensure more timely and accurate diagnosis, and reduce

costly unnecessary procedures, educational outreach to physicians and the general public remain critical.

Fecal Incontinence

At least 12 million Americans suffer from fecal incontinence. Incontinence is neither part of the aging process nor is it something that affects only the elderly. Incontinence crosses all age groups from children to older adults, but is more common among women and the elderly of both sexes. Often it is a symptom associated with various neurological diseases and many cancer treatments. Yet, as a society, we rarely hear or talk about the bowel disorders associated with spinal cord injuries, multiple sclerosis, diabetes, prostate cancer, colon cancer, uterine cancer, and a host of other diseases.

Courses of fecal incontinence include: damage to the anal sphincter muscles; damage to the nerves of the anal sphincter muscles or the rectum; loss of storage capacity in the rectum; diarrhea; or pelvic floor dysfunction. People who have fecal incontinence may feel ashamed, embarrassed, or humiliated. Some don't want to leave the house out of fear they might have an accident in public. Most attempt to hide the problem for as long as possible. They withdraw from friends and family, and often limit work or education efforts. Incontinence in the elderly burdens families and is the primary reason for nursing home admissions, an already huge social and economic burden in our aging population.

In November 2002, IFFGD sponsored a consensus conference entitled, *Advancing the Treatment of Fecal and Urinary Incontinence Through Research: Trial Design, Outcome Measures, and Research Priorities*. Among other outcomes, the conference resulted in six key research recommendations including more comprehensive identification of quality of life issues; improved diagnostic tests for affecting management strategies and treatment outcomes; development of new drug treatment compounds; development of strategies for primary prevention of fecal incontinence associated with childbirth; and attention to the stigmas that apply to individuals with fecal incontinence.

In December 2007, IFFGD collaborated with NIDDK, NICHD, and OMAR on the NIH State-of-the-Science Conference on the Prevention of Fecal and Urinary Incontinence in Adults. The goal of this conference was to assess the state of the science and outline future priorities for research on both fecal and urinary incontinence; including, the prevalence and incidence of fecal and urinary incontinence, risk factors and potential prevention, pathophysiology, economic and quality of life impact, current tools available to measure symptom severity and burden, and the effectiveness of both short and long term treatment. For fiscal year 2012, IFFGD urges Congress to review the Conference's Report and provide NIH with the resources necessary to effectively implement the report's recommendations.

Gastroesophageal Reflux Disease (GERD)

Gastroesophageal reflux disease, or GERD, is a common disorder affecting both adults and children, which results from the back-flow of acidic stomach contents into the esophagus. GERD is often accompanied by persistent symptoms, such as chronic heartburn and regurgitation of acid. Sometimes there are no apparent symptoms, and the presence of GERD is revealed when complications become evident. One uncommon but serious complication is Barrett's esophagus, a potentially precancerous condition associated with esophageal cancer. Symptoms of GERD vary from person to person. The majority of people with GERD have mild symptoms, with no visible evidence of tissue damage and little risk of developing complications. There are several treatment options available for individuals suffering from GERD. Nonetheless, treatment response varies from person to person, is not always effective, and long-term medication use and surgery expose individuals to risks of side-effects or complications.

Gastroesophageal reflux (GER) affects as many as one-third of all full term infants born in America each year. GER results from an immature upper gastrointestinal motor development. The prevalence of GER is increased in premature infants. Many infants require medical therapy in order for their symptoms to be controlled. Up to 25 percent of older children and adolescents will have GER or GERD due to lower esophageal sphincter dysfunction. In this population, the natural history of GER is similar to that of adult patients, in whom GER tends to be persistent and may require long-term treatment.

Gastroparesis

Gastroparesis, or delayed gastric emptying, refers to a stomach that empties slowly. Gastroparesis is characterized by symptoms from the delayed emptying of food, namely: bloating, nausea, vomiting, or feeling full after eating only a small amount of food. Gastroparesis can occur as a result of several conditions, including being

present in 30 percent to 50 percent of patients with diabetes mellitus. A person with diabetic gastroparesis may have episodes of high and low blood sugar levels due to the unpredictable emptying of food from the stomach, leading to diabetic complications. Other causes of gastroparesis include Parkinson's disease and some medications, especially narcotic pain medications. In many patients the cause of the gastroparesis cannot be found and the disorder is termed idiopathic gastroparesis. Over the last several years, as more is being found out about gastroparesis, it has become clear this condition affects many people and the condition can cause a wide range of symptom severity.

Cyclic Vomiting Syndrome

Cyclic vomiting syndrome (CVS) is a disorder with recurrent episodes of severe nausea and vomiting interspersed with symptom free periods. The periods of intense, persistent nausea, vomiting, and other symptoms (abdominal pain, prostration, and lethargy) lasts hours to days. Previously thought to occur primarily in pediatric populations, it is increasingly understood that this crippling syndrome can occur in a variety of age groups including adults. Patients with these symptoms often go for years without correct diagnosis. The condition leads to significant time lost from school and from work, as well as substantial medical morbidity. The cause of CVS is not known. Better understanding, through research, of mechanisms that underlie upper gastrointestinal function and motility involved in sensations of nausea, vomiting and abdominal pain is needed to help identify at risk individuals and develop more effective treatment strategies.

Support for Critical Research

IFFGD urges Congress to fund the NIH at level of \$35 billion for fiscal year 2012, an increase of 13 percent over fiscal year 2011. This funding level will help preserve the initial investment in healthcare innovation established by the American Recovery and Reinvestment Act of 2009. Strengthening and preserving our Nation's biomedical research enterprise fosters economic growth, and supports innovations that enhance the health and well-being of the Nation.

Concurrent with overall NIH funding, the IFFGD supports growth of research activities on functional GI and motility disorders, particularly through NIDDK and the Office of Research on Women's Health (ORWH). Increased support for NIDDK and ORWH will facilitate necessary expansion of the research portfolio on functional GI and motility disorders necessary to grow the medical knowledge base and improve treatment. Such support would also expedite the implementation of recommendations from the National Commission on Digestive Diseases. It is also vitally important for NIDDK to work to expand its research on the impact these disorders have on pediatric populations, in addition the adult population.

Following years of near level-funding at NIH, research opportunities have been negatively impacted across all NIH Institutes and Centers, including NIDDK. With the expiration of funding from the American Recovery and Reinvestment Act of 2009, medical researchers run the risk of "falling off a cliff", stalling, if not losing promising research from that 2 year period. For this reason, IFFGD encouraged support for initiatives such as the Cures Acceleration Network (CAN), authorized in the Patient Protection and Affordable Coverage Act. IFFGD urges the Subcommittee to show strong leadership in pursuing a substantial funding increase for CAN through the fiscal year 2012 appropriations process.

Thank you for the opportunity to present the views of the functional GI disorders community.

PREPARED STATEMENT OF THE INTERNATIONAL MYELOMA FOUNDATION

The International Myeloma Foundation (IMF) appreciates the opportunity to submit written comments for the record regarding fiscal year 2012 funding for myeloma cancer programs. The IMF is the oldest and largest myeloma foundation dedicated to improving the quality of life of myeloma patients while working toward prevention and a cure.

To ensure that myeloma patients have access to the comprehensive, quality care that they need and deserve, the IMF advocates ongoing and significant Federal funding for myeloma research and its application. The IMF stands ready to work with policymakers to advance policies and programs that work toward prevention and a cure for myeloma and for all other forms of cancer.

Myeloma Background

The second most common blood cancer worldwide, multiple myeloma (or myeloma) is a cancer of plasma cells in the bone marrow. It is called "multiple" myeloma be-

cause the cancer can occur at multiple sites in multiple bones. Each year approximately 20,000 Americans are diagnosed with myeloma and 10,000 lose their battle with this disease.

Although the incidence of many cancers is decreasing, the number of myeloma cases is on the rise. Once a disease of the elderly, it is now being found in increasing numbers in people under the age of 65. The 2009 President's Cancer Panel Report suggests that much of the increase in cancer incidence is being caused by environmental toxins. To give just one example supporting this hypothesis, a recently published study in *The Journal of Occupational and Environmental Medicine*, suggests a link between blood cancers like myeloma and exposure to the toxic dust at Ground Zero.

In recent years significant gains have been made, extending myeloma patients' lives and improving their quality of life. Furthermore, progress begun in myeloma is already helping patients with other blood cancers and even solid tumors. It is important to maintain that momentum.

—There is no cure for myeloma.

—Remissions are not always permanent.

—Additional treatment options are essential.

Living with the disease, myeloma patients can suffer debilitating fractures and other bone disorders, severe side effects of certain treatments, and other problems that profoundly affect their quality of life, and significantly impact the cost of their healthcare.

Sustain and Seize Cancer Research Opportunities

Myeloma research is producing extraordinary breakthroughs—leading to new therapies that translate into longer survival and improved quality of life for myeloma patients and potentially those with other forms of cancer as well. Myeloma was once considered a death sentence with limited options for treatment, but today myeloma is an example of the progress that can be made and the work that still lies ahead in the war on cancer. Many myeloma patients are living proof of what innovative drug development and clinical research can achieve—sequential remissions, long-term survival, and good quality of life. Our Nation has benefited immensely from past Federal investment in biomedical research at the National Institutes of Health (NIH) and the IMF advocates \$35 billion for NIH in fiscal year 2012.

A study in the *Journal of Clinical Oncology* projects that the number of new cancer cases diagnosed each year will jump 45 percent over the next 20 years. In multiple myeloma an even greater increase (57 percent) is projected, and we are already seeing increasing diagnoses in patients under age 65, including patients in their 30s, in what was once a rare disease of the elderly.

While a number of cancers have achieved 5-year survival rates of over 80 percent since passage of the National Cancer Act of 1971, significant challenges still remain for other cancers. In fact, nearly half of the 562,490 cancer deaths in 2010 were caused by just eight forms of cancer with 5-year survival rates of 45 percent or less—one of which is myeloma. Yet, myeloma and these other cancers have historically also received the least amount of Federal funding. As we have seen mortality rates of diseases such as breast cancer, prostate cancer, AIDS, and childhood leukemia greatly reduced through targeted, comprehensive, and well-funded programs that have led to earlier detection and superior forms of treatment, so too must we shine a brighter light on myeloma and the other seven deadly cancers to achieve this same goal for them. The IMF urges Congress to allocate \$5.740 billion to the National Cancer Institute (NCI) in fiscal year 2012 to continue our battle against myeloma.

Boost Our Nation's Investment in Myeloma Prevention, Early Detection, and Awareness

As the Nation's leading prevention agency, the Centers for Disease Control and Prevention (CDC) plays an important role in translating and delivering at the community level what is learned from research. Therefore, the IMF advocates \$6 million for the Geraldine Ferraro Blood Cancer Program. Authorized under the Hematological Cancer Research Investment and Education Act of 2002, this program was created to provide public and patient education about blood cancers, including myeloma.

With grants from the Geraldine Ferraro Blood Cancer Program, the IMF has successfully promoted awareness of myeloma, particularly in the African-American community and other underserved communities. IMF accomplishments include the production and distribution of more than 4,500 copies of an informative video which addresses the importance of myeloma awareness and education in the African-American community to churches, community centers, inner-city hospitals, and

Urban League offices around the country, increased African-American attendance at IMF Patient and Family Seminars (these seminars provide invaluable treatment information to newly diagnosed myeloma patients), increased calls by African-American myeloma patients, family members, and caregivers to the IMF's myeloma Hotline, and the establishment of additional support groups in inner city locations in the United States to assist underserved areas with myeloma education and awareness campaigns. Furthermore, the more than 90 IMF-affiliated patient support groups in the United States also made this effort their main goal during Myeloma Awareness Week in October 2005.

An allocation of \$6 million in fiscal year 2012 will allow this important program to continue to provide patients—including those populations at highest risk of developing myeloma—with educational, disease management and survivorship resources to enhance treatment and prognosis.

Additionally, the IMF is concerned about the consolidation plan for chronic disease programs at the CDC outlined in the President's fiscal year 2012 budget. This would be a substantial change in the chronic disease program where the Geraldine Ferraro Blood Cancer Program is currently housed. While we agree that there are health issue areas that share risk factors such as healthy eating and maintaining an active lifestyle that make sense to consolidate, unfortunately those are not risk factors for myeloma. We urge the CDC to maintain the programs like the Geraldine Ferraro Blood Cancer Program as a stand-alone program which would cease to exist under the proposed consolidation plan.

Conclusion

The IMF stands ready to work with policymakers to advance policies and support programs that work toward prevention and a cure for myeloma. Thank you for this opportunity to discuss the fiscal year 2012 funding levels necessary to ensure that our Nation continues to make gains in the fight against myeloma.

PREPARED STATEMENT OF THE INTERSTATE MINING COMPACT COMMISSION

We are writing in support of the fiscal year 2012 budget request for the Mine Safety and Health Administration (MSHA), which is part of the U.S. Department of Labor. In particular, we urge the Subcommittee to support a full appropriation for grants to States for safety and health training of our Nation's miners pursuant to section 503(a) of the Mine Safety and Health Act of 1977. MSHA's budget request for State grants is \$8.941 million. This is the same amount that has been appropriated for State training grants by Congress over the past 2 fiscal years and, as such, does not fully consider inflationary and programmatic increases being experienced by the States. We therefore urge the subcommittee to restore funding to the statutorily authorized level of \$10 million for State grants so that States are able to meet the training needs of miners and to fully and effectively carry out State responsibilities under section 503(a) of the Act.

The Interstate Mining Compact Commission is a multi-state governmental organization that represents the natural resource, environmental protection and mine safety and health interests of its 24 member States. The States are represented by their Governors who serve as Commissioners.

IMCC's member States are concerned that without full funding of the State grants program, the federally required training for miners employed throughout the United States will suffer. States are struggling to maintain efficient and effective miner training and certification programs in spite of increased numbers of trainees and the incremental costs associated therewith. State grants have flattened out over the past several years and are not keeping place with inflationary impacts or increased demands for training. The situation is of particular concern given the enhanced, additional training requirements growing out of the recently enacted MINER Act and MSHA's implementing regulations.

As you consider our request to increase MSHA's budget for State training grants, please keep in mind that the States play a particularly critical role in providing special assistance to small mine operators (those coal mine operators who employ 50 or fewer miners or 20 or fewer miners in the metal/nonmetal area) in meeting their required training needs.

We appreciate the opportunity to submit our views on the MSHA budget request as part of the overall Department of Labor budget. Please feel free to contact us for additional information or to answer any questions you may have.

PREPARED STATEMENT OF THE INTERSTITIAL CYSTITIS ASSOCIATION

Thank you for the opportunity to present the views of the Interstitial Cystitis Association (ICA) regarding the importance of public awareness activities and the importance of interstitial cystitis (IC) research.

ICA was founded in 1984 and remains the only nonprofit organization dedicated to improving the lives of those living with IC. The Association provides an important avenue for advocacy, research, and education in matters relating to IC. Since its founding, ICA has acted as a voice for those living with IC, including support groups and empowering patients. ICA advocates for the expansion of the IC knowledge-base and the development of new treatments, including investigator initiated research. Finally, ICA works doggedly to educate patients, healthcare providers, and the public at large about IC, including educational forums and information on how to live with this terrible condition.

IC is a condition that consists of recurring pain, pressure, or discomfort in the bladder and pelvic region and is often associated with urinary frequency and urgency. An estimated 4–12 million Americans have IC, approximately two-thirds of whom are women. The cause of IC is unknown and treatment options are limited. Diagnosis is made only after excluding other urinary/bladder conditions, possibly causing 1 or more years delay between onset of the symptoms and treatment. When healthcare providers are not properly educated about IC, patients may suffer for years before receiving an accurate diagnosis and appropriate treatment.

The effects of IC are pervasive and insidious, damaging work life, psychological well-being, personal relationships, and general health. The impact of IC on quality of life is equally as severe as rheumatoid arthritis and end-stage renal disease. Health-related quality of life in women with IC is worse than in women with endometriosis, vulvodynia, and overactive bladder. IC patients have significantly more sleep dysfunction, higher rates of depression, increased catastrophizing, anxiety, and sexual dysfunction.

Public Awareness and Education

As IC is a condition that often takes long periods to diagnosis, and this late diagnosis has such a major impact on the lives of patients, it is vitally important to continue to educate both the public and healthcare providers. The IC Education and Awareness Program at the Centers for Disease Control and Prevention (CDC) has played a major role in increasing the public's awareness of the devastating disease and is the only program in the Nation which promotes public awareness of IC. The public outreach of the CDC program includes public service announcements on major television networks and the Internet. Further, the CDC program has provided resources to make information on IC available to patients and the public through videos, booklets, publications, presentations, educational kits, websites, blogs, Facebook pages, and a YouTube channel. For providers, this program has included the development of an IC newsletter with information on IC treatments, research, news, and events; targeted mailings to providers; and exhibits at national medical conferences.

In order to continue these vitally important initiatives, which have reached thousands of Americans, it is critical that the CDC IC Education and Awareness Program be continued and receive a specific appropriation of \$660,000 for fiscal year 2012.

Research Through the National Institutes of Health

The National Institutes of Health (NIH), mainly through the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK), maintains a robust research portfolio on IC, including five recent major studies yielding significant new information. The RAND IC Epidemiology (RICE) study found that nearly 2.7–6.7 percent of adult women have symptoms consistent with IC and will prove important to the future development of clinical trials and epidemiological studies. The IC Genetic Twin study found environmental factors, rather than genetic factors, to be substantial risk factors of developing IC. The Events Preceding Interstitial Cystitis (EPIC) study has yielded significant information linking non-bladder conditions and infectious agents to the development of IC in many newly diagnosed IC patients. The findings of the EPIC study have been reinforced in a Northwestern University study which found that an unusual form of toxic bacterial molecule (LPS) has an impact the development of IC as a result of an infectious agent. Finally, the Urologic Pelvic Pain Collaborative Research Network (UPPCRN) has indicated promising results for a new therapy for IC patients.

Research currently underway and expected to begin in the near future also holds great promise to increase our understanding of IC, and thus find new treatments and cure. The Multidisciplinary Approach to the Study of Chronic Pelvic Pain (MAPP) Syndrome Research Network holds great potential to understanding the un-

derlying issues related to IC, other conditions possibly associated with IC, and new information related to flares of the condition. Additionally, the investigator-initiated research portfolio will continue to support research relating to fundamental issues relating to IC and pelvic pain, including new avenues for interdisciplinary research and new treatment options. Finally, NIH will continue to focus on developing new treatment and therapies to relieve this condition.

In order for this positive research to reach its full potential, it is essential NIH continue to receive funding which will allow it to continue and expand on past and current research. For this reason we recommend a funding level of \$35 billion for fiscal year 2012. We also recommend the continuation of the MAPP study and collaboration between NIDDK and the Office of Women's Health on issues related to IC.

Thank you for the opportunity to present the views of the interstitial cystitis community.

PREPARED STATEMENT OF THE IOWA STATEWIDE INDEPENDENT LIVING COUNCIL

I am contacting you regarding the proposed restructuring of the Independent Living funding that is outlined in President Obama's 2012 budget.

The seven Iowa Centers for Independent Living, along with all the other Centers for Independent Living across the country, need your help.

As you may know, Centers for Independent Living (CILs) are nonprofit organizations run by people with disabilities for people with disabilities. They are authorized by the Federal Rehabilitation Act. CILs help people with disabilities to remain independent in their own homes and communities, being productive and contributing members of society. CILs work to help people remain independent so they are not forced to live in institutions such as nursing homes. As I am sure you are aware, in the vast majority of cases it is much less costly for a person with a disability to remain in their own home and community rather than pay for them to be institutionalized, and even more importantly people with disabilities have the same right to live independently as do people who do not have a disability.

The Independent Living movement, CILs, and SILCs promote the philosophy of consumer control. Consumers, who are people with disabilities, control the operations of CILs and SILCs.

I would like to provide you with some education about the reality of what the President's proposed restructuring of Independent Living funding will do to many Centers for Independent Living (CILs). I am opposed to this restructuring because of the damage it will do to many CILs, including the very real possibility that many CILs will have to close their doors as they will not be able to fiscally operate under this new structure.

Currently, under the Federal Rehabilitation Act, CILs receive their Part C Federal Independent Living funding directly from the Federal Rehabilitation Services Administration (RSA). The Federal Part B funds are given to the States, in most cases to the State Vocational Rehabilitation Services (VR) agency, and the VR does contracts with the CILs and the Statewide Independent Living Council (SILC) for these Part B Federal funds. The Federal Part C funds do not require a State match as they come directly from RSA at the Federal level to the individual CILs. The Part B funding does require a State match as it comes directly to the state VR agency.

Combining the Federal Part B and the Federal Part C Independent Living funding, and making these funds into a new block grant to States for Independent Living funding, is not acceptable for a number of reasons, and I would like to outline those reasons.

Combining these funds into a block grant and giving them to States will significantly reduce, if not eliminate, consumer control of independent living programs. Prior to the Part C funds being given to RSA to distribute directly to CILs, the funds were given out in grants to States. There were numerous problems with the State administering these grant funds, which is why the funding structure was changed to Part C going directly from RSA to CILs. Here are some examples of what happened in the past, and these problems will also occur under the President's proposed block grant funding:

—Under the past IL grant process, if the State had a freeze on hiring or travel, they would also make the CILs have a freeze on travel and hiring. This meant the CILs could not hire staff when needed, nor could they travel when needed. So even though the consumer controlled CIL Board directed the CIL Executive Director to hire a new staff, or directed that staff was to travel to attend a national conference, the State would not allow the CIL to do these things and would not provide the money to do these things, even though these things were

an allowable use of the Federal grant funds. The State agency controlled the CIL, the Consumer Board did not have any control.

- In many States, the Vocational Rehabilitation Services agency has procedures for reimbursing funds to the CILs, and in many States CILs would submit documentation for reimbursement and it would take 3, 4 or 5 months for the VR agency to get the money back to the CIL, which caused a great hardship for CILs to be able to keep their doors open. Here is one true example. One CIL Director re-financed his own house to take out a loan to meet staff payroll until the CIL received the reimbursement funds for their expenses from the State VR agency. Currently, I know this is an issue with the Federal Part B funds that the VR agencies give to CILs. It can take up to 4 or 5 months for a CIL to get reimbursed for their Part B funds. Fortunately, many of those CILs also get Federal Part C funds directly from RSA so they have money to cover their expenses until they get the Part B reimbursement check from VR. If the President's proposal becomes reality, there are many CILs that will most likely have to close as they will not have the working capital to pay their bills and then wait 4–5 months to get reimbursed by the VR agency.

There are additional concerns to consider.

- VR agencies are already under stress from State budget cuts, and it takes VR staff time to be able to do contracts and reimbursements for CILs. If these contracts become bigger, VRs will have to hire additional staff to manage these funds and do the contracts with the CILs. Where will the money come from for the VR agency to do this? Will it be taken out of the combined Part B and Part C funds, which means less funds going to CILs for direct consumer partner services, and less money to SILCs to be able to operate?
- Currently only the Part B funds require a State match. If you combine B and C into one block grant, will State match be required for this total amount? If so, where are States going to get the State funds to match the additional Part C funds? Many States can barely find the match for the Part B funds, so it is possible that States will not have funds to match the Part C funds too. That means the State will not get the Part C funds, and Centers will not have enough funding to keep their doors open.
- Providing direct funding to CILs is required by the Federal Rehabilitation Act, and for the President's budget proposal to be enacted, the Rehabilitation Act would have to be significantly altered and then reauthorized.

These are very real and disturbing concerns. I would like to know that President Obama, as well as the Federal legislators, are looking at these concerns and how to address them before going ahead with the President's proposed restructuring. There must be a better way to do this that will maintain consumer partner control of CIL operations, and that will allow CILs to fiscally operate without risk of having to close their doors, and/or reduce staff and services to consumer partners.

PREPARED STATEMENT OF THE JOINT ADVOCACY COALITION OF THE: ASSOCIATION FOR CLINICAL RESEARCH TRAINING, ASSOCIATION FOR PATIENT-ORIENTED RESEARCH, AND CLINICAL RESEARCH FORUM

The Association for Clinical Research Training (ACRT), the Association for Patient-Oriented Research (APOR), the Clinical Research Forum (CR Forum), and the Society for Clinical and Translational Science (SCTS) represent a coalition of professional organizations dedicated to improving the health of the public through increased clinical and translational research, and clinical research training. United by the shared priorities of the clinical and translational research community, ACRT, APOR, CR Forum, and SCTS advocate for increased clinical and translational research at the National Institutes of Health (NIH), the Agency for Healthcare Research and Quality (AHRQ), and other Federal science agencies.

On behalf of ACRT, APOR, CR Forum, and SCTS, I would like to thank the Subcommittee for their continued support of clinical and translational research, and clinical research training. The creation of the Patient-Centered Outcomes Research Institute and National Center for the Advancement of Translational Science in healthcare reform will provide a much-needed and greatly appreciated boost to comparative effectiveness research (CER) at the Federal level, as well as the organization of the new National Center for Translational Science (NCATS). As outlined by NIH Director Dr. Francis Collins in his five priorities for NIH, the translation of basic science to clinical treatment is an integral component of modern biomedical research, and a necessity to developing the treatments and cures of tomorrow.

Today, I would like to address a number of issues that cut to the heart of the clinical and translational research community's priorities, including the Clinical and

Translational Science Awards program (CTSA) at NIH, career development for clinical researchers, and support for CER at the Federal level.

As our Nation's investment in biomedical research expands to provide more accurate and efficient treatments for patients, we must continue to focus on the translation of basic science to clinical research. The CTSA program at NIH is quickly becoming an invaluable resource in this area, but full funding is needed if we are to truly take advantage of the CTSA infrastructure.

Fully Funding and Support for the CTSA Program at NIH

With its establishment in 2006, the CTSA program at NIH began to address the need for increased focus on translational research, or research that bridges the gap between basic scientific discoveries and the bedside. Originally envisioned as a consortium of 60 academic institutions, the CTSA program currently funds 55 academic medical research institutions nationwide, and is set to expand to the full 60 by the end of 2011. The CTSA program has an explicit goal of improving healthcare in the United States by transforming the biomedical research enterprise to become more effectively translational. Specifically, the CTSA program hopes to (1) improve the way biomedical research is conducted across the country; (2) reduce the time it takes for laboratory discoveries to become treatments for patients; (3) engage communities in clinical research efforts; (4) increase training and development in the next generation of clinical and translational researchers; and (5) accelerate T1 translational science.

Although the promise of the CTSA program is recognized both nationally and internationally, it has suffered from a lack of proper funding along with NIH, and the National Center for Research Resources (NCRR). In 2006, 16 initial CTSA programs were funded, followed by an additional 12 in 2007 and 14 in 2008, 4 in 2009, and 9 in 2010. Level-funding at NIH curtailed the growth of the CTSA programs, preventing recipient institutions from fully implementing their programs and causing them to drastically alter their budgets after research had already begun. If budgets continue to decline, the CTSA programs risk jeopardizing not only new research but also the research begun by first, second, and third generation CTSA programs. Professional judgments have determined full funding to be at a level of \$700 million.

We recognize the difficult economic situation our country is currently experiencing, and greatly appreciate the commitment to healthcare Congress has demonstrated through stimulus funding, the fiscal year 2011 appropriations process, and through healthcare reform. The CTSA programs are currently funding 55 academic research institutions nationwide at a level of \$464 million, with the goal of full implementation by late 2011. In order to reach full implementation of 60 CTSA programs by late 2011, and to realize the promise of the CTSA programs in transforming biomedical research to improve its impact on health, it is imperative that the CTSA program receive funding at the level of \$700 million in fiscal year 2012. Without full funding, more CTSA programs will be expected to operate with fewer resources, curtailing their transformative promise.

A major part of the CTSA program's promise lies in its synergy with all of NIH's Institutes and Centers (ICs), and the acceleration and facilitation of the ICs' impact. The translation of laboratory research to clinical treatment directly benefits patients suffering from complex diseases and all fields of medicine. The CTSA program has created improved translational research capacity and processes from which all NIH's ICs stand to benefit. The development of a formal NIH-wide plan to link all ICs to the CTSA program would efficiently capitalize on NIH investment and the new opportunities presented by the advent of NCATS for clinical and translational science.

It is our recommendation that the Subcommittee support full implementation of the CTSA program by providing \$700 million in fiscal year 2011, and we ask that the Subcommittee support the development of a formal NIH-wide plan to integrate the CTSA programs to all of NIH's Institutes and Centers.

Continuing Support for Research Training and Career Development Programs Through the K Awards

The future of our Nation's biomedical research enterprise relies heavily on the maintenance and continued recruitment of promising young investigators. Clinical investigators have long been referred to as an "endangered species", as financial barriers push medical students away from research. This trend must be arrested if we are to continue our pursuits of better treatments and cures for patients.

The K Awards at NIH and AHRQ provide much-needed support for the career development of young investigators. As clinical and translational medicine takes on increasing importance, there is a great need to grow these programs, not reduce them. Career development grants are crucial to the recruitment of promising young investigators, as well as to the continuing education of established investigators. Reduced

commitment to the K-12, K-23, K-24, and K-30 awards would have a devastating impact on our pool of highly trained clinical researchers. Even with the full implementation of the CTSA program, it will be critical for institutions without CTSAs to retain their K-30 Clinical Research Curriculum Awards, as the K-30s remain a highly cost-effective method of ensuring quality clinical research training. ACRT, APOR, CRF, and SCTS strongly support the ongoing commitment to clinical research training through K Awards at NIH and AHRQ.

We ask the Subcommittee to continue their support for clinical research training and career development through the K Awards at NIH and AHRQ, in order to promote and encourage investigators working to transform biomedical science.

Continuing Support for CER

Comparative effectiveness research or “CER” emerged at the forefront of the healthcare reform debate, capturing the interest of lawmakers and the American people. CER is the evaluation of the impact of different options that are available for treating a given medical condition for a particular set of patients. This broad definition can include medications, behavioral therapies, and medical devices among other interventions, and is an important facet of evidence-based medicine. On behalf of ACRT, APOR, CR Forum, and SCTS, I would like to thank the Senate for the creation of the Patient-Centered Outcomes Research Institute in the Patient Protection and Affordable Care Act, as well as the \$1.1 billion included for CER at NIH and AHRQ in the American Recovery and Reinvestment Act (ARRA). Both AHRQ and NIH have long histories of supporting CER, and the standards for research instituted by agencies like NIH and AHRQ serve as models for best practices worldwide. Not only are these agencies experienced in CER, they are universally recognized as impartial and honest brokers of information.

We are pleased that Congress recognizes the importance of these activities and believe that the peer review processes and infrastructure in place at NIH and AHRQ ensure the highest quality CER. We believe that collaboration between the Patient-Centered Outcomes Research Institute, NIH, and AHRQ will motivate all Federal CER efforts. In addition to support for the CTSA program at NIH, we encourage the Subcommittee to provide continued support for Patient-Centered Health Research at AHRQ.

Thank you for the opportunity to present the views and recommendations of the clinical research training community. On behalf of ACRT, APOR, CR Forum, and SCTS, I would be happy to be of assistance as the appropriations process moves forward.

PREPARED STATEMENT OF LIONS CLUBS INTERNATIONAL

Lions Clubs International (LCI) its official charity arm, Lions Clubs International Foundation (LCIF), have been world leaders in serving the vision, hearing, youth development, disability and humanitarian needs of millions of people in America and around the world, and we work closely with other NGOs. Since LCIF was founded in 1968, it has awarded more than 9,000 grants, totaling more than \$700 million for service projects ranging from affordable hearing aids to diabetes-prevention. All Administrative costs are paid for through interest earned on investments, allowing LCIF to maximize out impact on the community and demonstrating the motto “We Serve.”

Our current 1.35 million-member global membership, representing over 206 countries, serves communities through the following ways: protect and preserve sight; provide disaster relief; combat disability; promote health; and serve youth. The 12,000 individual clubs representing over 375,000 individual citizens in North America are constantly expanding to add new programs and its volunteers are working to bring health services to as many communities as possible.

LCI represents the largest and most effective NGO service organization presence in the world. Awarded and recognized as the #1 NGO organization for partnership globally by The Financial Times 2007, LCI also holds a four star (highest) rating from the CharityNavigator.com (an independent review organization).

Today, we face many complex challenges in the health and education sector, from preventable diseases that cause blindness in children to bullying, violence, and drug use among school-aged children. I will offer a brief summary of recommendations in programs under the general jurisdiction of the Labor-HHS-Education Subcommittee.

Domestic Sight Services

Through our network of foundations and programs across America, LCI remains the single largest provider of charitable vision care, eyeglasses and hearing care services to needy and indigent people. Some of our major sight initiatives include:

- The Sight for Kids Program in collaboration with Johnson and Johnson. The program has provided 6 million vision screenings and eye-health education programs for children.
- Core 4 Preschool Vision Screening program enables LCI to conduct screenings for children in preschools. The program strives to deliver early detection and treatment for the most common vision disorders that can lead to amblyopia or “lazy eye.” LCIF has also provided grants and services to those affected by eye conditions that cannot be improved medically.
- LCI Clubs sponsored “United We Serve Health Week” events around the country. These Health Week efforts, in conjunction with the White House, were effective in bringing awareness to vision health issues.

National Eye Institute—Vision Health Recommendations

LCI believes that vision loss is a major public health problem that increases healthcare costs and reduces productivity and quality of life for millions of Americans. LCI played an important role in the creation of a free-standing eye institute separate from the then-National Institute for Neurological Diseases and Blindness. The National Eye Institute Act was signed into law by President Johnson in 1968 as the Nation’s lead Institute within the NIH to prevent blindness and save and restore vision of all Americans. NEI-funded research is resulting in treatments and therapies that save vision and restore sight, resulting in reduced healthcare costs and higher productivity.

LCI is concerned that proposals to reduce NIH funding to fiscal year 2008 levels would result in NEI funding for fiscal year 2011 at \$667 million, or a \$30 million loss. This would result in 43 fewer investigator-initiated research grants to save or restore vision. According to the National Association Eye and Vision Research, this funding reflects little more than 1 percent of the \$68 billion annual cost of eye disease and vision impairment in the United States.

LCI supports fiscal year 2012 NIH funding at \$35 billion. This funding level would ensure that NIH can maintain the number of multi-year investigator-initiated research grants, and enables NEI to build upon its record of basic clinical/translational research. We also support an increase in NEI funding above the 1.8 percent proposed by the President.

Vision 2020 USA Partnership

VISION 2020 USA members, including Lions Clubs International, share a commitment to blindness prevention, preserving sight, and ensuring that all individuals receive the vision and eye healthcare they need and deserve. We are particularly interested in ensuring that Congress provides for fiscal year 2012 to support the following programs and initiatives:

- Sustainment of at least \$3.23 million for vision and eye health initiatives at the Centers for Disease Control and Prevention (CDC)
- Support of the Maternal and Child Health Bureau’s (MCHB) National Center for Children’s Vision and Eye Health

Vision-related conditions affect people across the lifespan from childhood through elder years. Fortunately, in children, many serious ocular conditions—such as amblyopia, nearsightedness, farsightedness, and astigmatism—are treatable, if diagnosed at an early stage. Yet, too many children do not receive vision screenings or follow-up comprehensive eye examinations and treatment. More than 80 million Americans are at risk for a potentially blinding eye disease such as diabetic retinopathy, glaucoma, cataract, and age-related macular degeneration. If nothing is done, the number of blind Americans is expected to double by 2030.

With fiscal year 2012 appropriations that maintain current funding for vision and eye health efforts of the CDC and increased resources for the NIH and NEI, these Federal vision and eye health partners will have the resources they need to sustain and expand their respective efforts and programs to advance the prevention, diagnosis, and treatment of vision problems and eye disease.

Lions Affordable Hearing Aid Project (AHAP)

LCI is committed to fighting hearing loss as well as blindness. By listening to community health organizations across the country, Lions Clubs International and their volunteer members became aware of the lack of quality and affordable hearing care, especially for people with incomes below or at 200 percent of the poverty level.

Many people have been unable to access other personal and family resources to purchase hearing aids, and have been denied State and Federal assistance. Fourteen centers have been working to expand output in this area as demand continues to rise with a network of mobile health units and community based programs that screen more than 2 million people each year and provide hearing aids to 14,000 low income patients.

The statistics are unacceptable: 31 million persons in the United States experience some form of hearing loss, yet only 7.3 million opt to use hearing aids. According to audiology researchers, the market penetration for hearing aids is about 23.6 percent. For every four patients that enter a practice needing hearing aids, only one will purchase them. The median price tag is \$1,900 (2005) for a digital hearing aid and prices go as high as \$4,000. State Foundations, public health departments, and aging departments are in need of assistance in this area.

With the recent 25–30 percent increase in people seeking assistance for hearing aids, there is an immediate public imperative to address the problem. Federal dollars are stretched, but Federal support in this area would have significant public health dividends in difficult economic times.

“LIONS QUEST”/EDUCATION/HEALTH PROGRAMS

LCIF’s youth development initiatives, known collectively as “Lions Quest,” have been a prominent part of school-based K–12 programs since 1984. Fulfilling its mission to teach responsible decisionmaking, effective communications and drug prevention, Lions Quest has been involved in training more than 350,000 educators and other adults to provide services for over 11 million youth in programs covering 43 States. LCIF currently invests more than \$2 million annually in supporting life skills training and service learning, and that funding is matched by local Lions, schools and other partners.

Lions Quest curricula incorporate parent and community involvement in the development of health and responsible young people in the areas of: life skills development (social and emotional learning), character education, drug prevention, service learning, and bullying prevention. There is even a physical fitness component to this program that can assist Federal goals of reducing obesity in school-aged children.

These Lions Quest programs provide strong evidence of decreased drug use, improved responsibility for students own behavior, as well as stronger decisionmaking skills and test scores in math and reading. In August 2002, Lions Quest received the highest “Select” ranking from the University of Illinois at Chicago-based Collaborative for Academic, Social and Emotional Learning (CASEL) for meeting standards in life skills education, evidence of effectiveness and exemplary professional development.

Lions Quest has extensive experience with Federal programs. Lions Quest Skills for Adolescence received a “Promising Program” rating from the U.S. Department of Education Safe and Drug Free Schools and a “Model” rating from the U.S. Department of Health and Human Services Substance Abuse and Mental Health Services Administration (SAMHSA).

Lions Quest also has extensive experience of partnering with State service commissions to reach more schools and engage more young people in service learning. Successful partnerships have been active in Michigan, New York, Oklahoma, Tennessee and West Virginia with progress being made in Texas and Ohio.

Social and Emotional Learning Programs

In addition, Lions Clubs recommends Congressional support for social and emotional learning (SEL) programs that stimulate growth among schools nationwide through distribution of materials and teacher training, and to create opportunities for youth to participate in activities that increase their social and emotional skills. Not only do SEL curricula contribute to the social and emotional development of youth, but they also provide invaluable support to students’ school success, health, well-being, peer and family relationships, and citizenship. While still conducting scientific research and reviewing the best available science evidence, over time Lions Clubs and its SEL partners have increasingly worked to provide SEL practitioners, trainers and school administrators with the guidelines, tools, informational resources, policies, training, and support they need to improve and expand SEL programming.

Overall, SEL training programs and curricula have outstanding benefits for school-aged children:

- SEL prevents a variety of problems such as alcohol and drug use, violence, truancy, and bullying. SEL programs for urban youth emphasize the importance of cooperation and teamwork.

- Positive outcomes increase in students who are involved in social and emotional learning programming by an average of 11 percentile points over other students.
- With greater social and emotional desire to learn and commit to schoolwork, participants benefit from improved attendance, graduation rates, grades, and test scores.

CONCLUSION

Lions Clubs remains committed to domestic activities such as major sight initiatives and positive youth development and youth service programs. Today we face great health and educational challenges, and Lions Clubs International understands the importance not only of community service but of instilling those among members of our next generation. The success of nonprofit entities such as Lions Clubs show what the service sector can do for economic and social development of communities that are especially hard hit by the recession, and we are committed to forming more effective alliances and partnerships to increase our domestic impact.

PREPARED STATEMENT OF THE MARCH OF DIMES FOUNDATION

The 3 million volunteers and nearly 1,300 staff members of the March of Dimes Foundation appreciate the opportunity to submit Federal funding recommendations for fiscal year 2012.

The March of Dimes was founded in 1938 by President Franklin D. Roosevelt to support research to prevent polio. Today, the Foundation aims to improve the health of women, infants and children by preventing birth defects, premature birth, and infant mortality through scientific research, community services, education and advocacy.

The March of Dimes is a unique partnership of scientists, clinicians, parents, members of the business community and other volunteers affiliated with 51 chapters and 213 divisions in every State, the District of Columbia and Puerto Rico. Additionally, in 1992, the March of Dimes extended its mission globally and now operates through partnerships in 33 countries on four continents.

The March of Dimes is aware that the current fiscal environment necessitates restrictions on Federal funding increases and program expansions. However, it is our hope that these budgetary limitations will not put at risk our vital mission on which affected families rely. Therefore, the March of Dimes recommends the following funding levels for programs and initiatives that are essential investments in maternal and child health.

PRETERM BIRTH

In 2008, one in eight infants was born preterm (before 37 weeks). Preterm birth is the leading cause of newborn mortality (death within the first month) and the second leading cause of infant mortality (death within the first year). In 2009, the National Center for Health Statistics (NCHS) reported that the primary reason for the higher infant mortality rate in the United States compared to other high resource countries is the greater percentage of preterm births—12.4 percent in the United States compared to 5.5 percent in Ireland. But survival alone does not necessarily result in good health for these infants. Among those who survive, one in five faces health problems that persist for life. Prematurity-related conditions include cerebral palsy, intellectual disabilities, chronic lung disease, blindness and deafness. A comprehensive report published by the Institute of Medicine in 2007 estimated that preterm births cost the United States more than \$26 billion in 2005 alone, with costs climbing each year.

As a result of legislation enacted in 2006 (Public Law 109–450), the U.S. Surgeon General sponsored a conference in 2008 of more than 200 of the country's foremost experts that convened for 2 days to develop a strategy to address the costly and serious problems of preterm birth. The meeting resulted in an action plan that included several overarching themes and recommendations. Among the most important were the enhancement of biomedical and epidemiological research and strengthening our Nation's data resources that document the health status of pregnant women and infants. The Foundation's funding requests regarding preterm birth are based on these recommendations.

National Institutes of Health

The March of Dimes commends members of the Subcommittee for their continuing support of the National Children's Study (NCS). For fiscal year 2012, the Foundation supports the President's funding recommendation of \$193.9 million for the NCS

and we urge the Subcommittee to support this recommendation as well. The NCS is the largest and most comprehensive study of children's health and development ever planned in the United States. The 37 "vanguard centers" have recruited nearly 3,000 participants thus far and more than 650 children have been born into the study. When fully implemented, this study will follow a representative sample of 100,000 children in the United States from before birth until age 21. The data from this important study will help scientists at universities and research organizations across the country and around the world identify precursors of diseases and develop new strategies for treatment and prevention. Specifically, the first data generated by the NCS will provide information concerning disorders of birth and infancy, including preterm birth and its health consequences. The Foundation remains committed to supporting a well-designed NCS that promotes research of the highest quality and asks the Subcommittee to do the same.

Eunice Kennedy Shriver National Institute of Child Health and Human Development (NICHD)

For fiscal year 2012, the March of Dimes recommends at least \$1.35 billion for the NICHD. This \$30 million increase compared to the fiscal year 2011 enacted level will enable NICHD to expand its support for preterm birth-related research through the Maternal-Fetal Medicine Units, Neonatal Research Network, and Genomic and Proteomic Network for Preterm Birth Research. In addition, it will allow for planning grants to begin establishing a network of integrated trans-disciplinary research centers, as recommended by the Institute of Medicine report and the aforementioned 2008 Surgeon General's Conference. The causes of preterm birth are multi-faceted and necessitate a coordinated and collaborative approach integrating many disciplines. These trans-disciplinary centers would serve as a national resource for investigators to design and share new research approaches and strategies to comprehensively address preterm birth.

Centers for Disease Control and Prevention—Preterm Birth

The National Center for Chronic Disease Prevention and Health Promotion's Safe Motherhood Program works to promote optimal reproductive and infant health. In 2009, CDC created a robust research agenda to prevent preterm birth by improving derivation of accurate data to understand preterm birth; developing, implementing and evaluating prevention methods; and conducting targeted etiologic and epidemiologic studies. For fiscal year 2012, the March of Dimes recommends a \$6 million increase in the CDC's preterm birth budget compared to the fiscal year 2011 enacted level (for a total of \$8 million) to strengthen our national data systems and to expand preterm birth research as authorized by the PREEMIE Act (Public Law 109-450).

Centers for Disease Control and Prevention—National Center for Health Statistics

The National Center for Health Statistics' (NCHS) vital statistics program collects birth and death data that are used to monitor the Nation's health status, set research and intervention priorities, and evaluate the effectiveness of existing health programs. It is imperative that data collected by NCHS be comprehensive and timely. Unfortunately, one-quarter of the States and territories lack the capacity to use the most recent (2003) birth certificate format and only two-thirds have adopted the most recent (2003) death certificate format. The March of Dimes supports the President's recommendation to provide \$162 million for the NCHS in fiscal year 2012 and urges the Subcommittee to support this recommendation in both the bill language and in the accompanying committee report as well.

Health Resources and Services Administration—Healthy Start

The Maternal and Child Health Bureau's Healthy Start Program is a collection of community-based projects focused on reducing infant mortality, low birth weight, and racial disparities in perinatal outcomes among high-risk populations by strengthening local health systems and resources. Communities with Healthy Start programs have seen significant improvements in perinatal health outcomes. The March of Dimes supports the President's recommendation to provide \$105 million for Healthy Start in fiscal year 2012 and urges the Subcommittee to support this recommendation as well.

BIRTH DEFECTS

According to the Centers for Disease Control and Prevention, an estimated 120,000 infants in the United States are born with major structural birth defects each year. Genetic or environmental factors, or a combination of both, can cause various birth defects; yet the causes of more than 70 percent are unknown. Many

birth defects result in childhood and adult disability that require costly, lifelong treatments and special care. Additional Federal resources are sorely needed to support research to discover causes of all birth defects and for the development of effective interventions to prevent or at least reduce their prevalence.

CDC's National Center on Birth Defects and Developmental Disabilities (NCBDDD)

The NCBDDD conducts programs to protect and improve the health of children by preventing birth defects and developmental disabilities and by promoting optimal development and wellness among children with disabilities. For fiscal year 2012, the March of Dimes requests at least \$144 million for NCBDDD. In addition, we encourage the Subcommittee to allocate an additional \$5 million specifically to support birth defects research and surveillance and an additional \$2 million specifically to support folic acid education. A source for this \$7 million in additional funding could be the Prevention and Public Health Fund. Investing in the work of the NCBDDD will promote wellness and preventive strategies aimed at children, reduce health disparities, and enable CDC to more effectively support transition to adulthood for children with lifelong disabilities.

Allocating an additional \$5 million to support genetic analysis of the research samples already obtained through the NCBDDD's National Birth Defects Prevention Study—the largest case-controlled study of birth defects ever conducted—would be a sound investment. This analysis would enable researchers to begin the work needed to translate their findings into effective birth defects intervention and treatment programs. The study has already yielded rich results. In 2009 alone, 29 articles regarding risk factors for birth defects—for example maternal diabetes, obesity, use of certain medications, and smoking—were published in medical and health journals. In addition, this investment would make possible the continuation of NCBDDD's State-based birth defects surveillance grant program. Surveillance is the backbone of the public health network and its support should be a Subcommittee priority. Because of the current fiscal situation facing many States, funding for State-based surveillance systems is in jeopardy and requires increased Federal support to ensure the survival of essential birth defects surveillance programs.

Allocating an additional \$2 million to NCBDDD will allow the CDC to expand its effective national education campaign aimed at reducing the incidence of spina bifida and anencephaly by promoting consumption of folic acid. Since the institution of fortification of U.S. enriched grain products with folic acid, the rate of neural tube defects has decreased by 26 percent. However, CDC estimates that up to 70 percent of neural tube defects could be prevented if all women of childbearing age consumed 400 micrograms of folic acid daily. To raise awareness among women of childbearing age and thereby increase the use of folic acid, NCBDDD's national education campaign must be expanded.

The March of Dimes is very concerned about the Administration's recommendation that the NCBDDD's budget lines be consolidated into three categories: Child Health and Development, Health and Development for People with Disabilities, and Public Health Approach to Blood Disorders. As proposed, the Birth Defects and Developmental Disabilities budget line would be renamed Child Health and Development and existing sub-categories would be eliminated (e.g. Birth Defects, Fetal Alcohol Syndrome, Folic Acid). While the March of Dimes recognizes and supports program flexibility for CDC management, we are concerned that the title "Child Health and Development" fails to make clear the overall purpose of the programs covered, masking the urgency and importance of the need for ongoing support from Congress. We urge the Subcommittee to modify the Administration's proposal by retaining the term "Birth Defects" as a sub-line with the category "Child Health and Development." We believe this adjustment is needed to ensure that the content of these essential programs to reduce birth defects is clearly articulated.

NEWBORN SCREENING

Newborn screening is a vital public health activity used to identify genetic, metabolic, hormonal and functional disorders in newborns so that treatment can be provided. Screening detects conditions in newborns that, if left untreated, can cause disability, developmental delays, intellectual disabilities, serious illnesses or even death. If diagnosed early, many of these disorders can be successfully managed. Across the Nation, State and local governments are experiencing significant budget shortfalls. Because of this fiscal pressure, discontinuing screening for certain conditions or postponing the purchase of necessary technology is a serious threat that, if left unresolved, will put infants at risk of permanent disability or even death. For fiscal year 2012, an additional \$5 million for HRSA's heritable disorders program, as authorized by the Newborn Screening Saves Lives Act (Public Law 110-204), is necessary to increase support for State efforts to improve screening, enhance coun-

selling, and increase capacity to reach and educate health professionals and parents about newborn screening programs and follow-up services.

OTHER

Agency for Health Research and Quality (AHRQ)

AHRQ supports research to improve healthcare quality, reduce costs and broaden access to essential health services. For fiscal year 2012, the March of Dimes recommends \$405 million total for AHRQ to continue its important work, including the development and dissemination of maternal and pediatric quality measures and comparative effectiveness research. Moreover, with the historic enactment of health reform last year, AHRQ's research is needed more than ever to build the evidence-base that will be used to improve health and healthcare coverage.

Health Resources and Services Administration—Maternal and Child Health Block Grant

Title V of the Social Security Act, the Maternal and Child Health Block Grant, supports a growing number of community-based programs (e.g. home visiting, respite care for children with special healthcare needs, and supplementary services for pregnant women and children enrolled in Medicaid and the State Children's Health Insurance Program), but Federal support has not kept pace with increased enrollment and demand for these services. For fiscal year 2012, the March of Dimes recommends \$700 million for the Maternal and Child Health Block Grant—\$44 million more than the fiscal year 2011 enacted level.

CDC National Immunization Program

Infants are particularly vulnerable to infectious diseases, which is why it is critical to protect them through immunization. In 2008, the national estimated immunization coverage among children 19–35 months of age was 76 percent. The CDC's National Immunization Program supports States, communities and territorial public health agencies through grants to reduce the incidence of disability and death resulting from vaccine-preventable diseases. The March of Dimes is requesting \$685 million in fiscal year 2012 for the National Immunization Program.

CDC Polio Eradication

Since its creation as an organization dedicated to research and services related to polio, the March of Dimes has been committed to the eradication of this disabling disease. We support the Administration's Global Polio Eradication Strategic Plan for the remaining endemic countries, and urge the Subcommittee to approve the President's request for \$112 million in fiscal year 2012 to support CDC's Polio Eradication Program.

CLOSING

Thank you for the opportunity to testify on the federally supported programs of highest priority to the March of Dimes. The Foundation's volunteers and staff in every State, the District of Columbia and Puerto Rico look forward to working with Members of this Subcommittee to secure the resources needed to improve the health of the Nation's mothers, infants and children.

MARCH OF DIMES FISCAL YEAR 2012 FEDERAL FUNDING PRIORITIES

Program	Fiscal year 2011 funding (w/pre- vention fund add-on where applicable)	March of Dimes fiscal year 2012 request
National Institutes of Health (Total)	\$30.77 B	\$35 B
National Children's Study	191.05 M	193.9 M
Common Fund	543.02 M	556.9 M
National Institute of Child Health and Human Development	1.32 B	1.35 B
National Human Genome Research Institute	511.5 M	524.8 M
National Center on Minority Health and Disparities	209.71 M	214.6 M
Centers for Disease Control and Prevention (Total)	6.26 B	7.7 B
Birth Defects Research & Surveillance	20.3 M	25.3 M
Folic Acid Campaign	2.8 M	4.8 M
Immunization	525.57 M	685 M
Polio Eradication	101.6 M	112 M
Preterm Birth (Safe Motherhood)	1.97 M	8 M
National Center for Health Statistics	168.68 M	162 M

MARCH OF DIMES FISCAL YEAR 2012 FEDERAL FUNDING PRIORITIES—Continued

Program	Fiscal year 2011 funding (w/pre- vention fund add-on where applicable)	March of Dimes fiscal year 2012 request
Health Resources and Services Administration (Total)	6.29 B	7.65 B
Maternal and Child Health Block Grant	656.32 M	700 M
Newborn Screening	9.95 M	15 M
Newborn Hearing Screening	18.88 M	19 M
Community Health Centers	2.48 B	2.56 B
Healthy Start	104.36 M	105 M
Agency for Healthcare Research and Quality (Total)	392.05 M	405 M

PREPARED STATEMENT OF THE MEALS ON WHEELS ASSOCIATION OF AMERICA

Thank you for the opportunity to present testimony to your subcommittee concerning fiscal year 2012 funding for Senior Nutrition Programs administered by the Administration on Aging (AoA) within the U.S. Department of Health and Human Services (HHS). I am Enid A. Borden, President and CEO of the Meals On Wheels Association of America (MOWAA), the oldest and largest national organization representing local, community-based Senior Nutrition Programs—both congregate and home-delivered (commonly referred to as Meals On Wheels)—and the only national organization and network dedicated solely to ending senior hunger in America. I speak on behalf not only of that national network of Senior Nutrition Programs but also for the hundreds of thousands of seniors in communities across this Nation who depend upon those programs for access to nutritious meals. I speak for them because many are behind closed doors, invisible and without a voice of their own. But it is not only for those particular seniors that I bring our concerns before you. I also speak for those other seniors who like their peers need meals, but who do not receive them, not because we lack the infrastructure and expertise to serve them but because our Senior Nutrition Programs lack the adequate financial resources to provide them. At MOWAA we call those individuals the hidden hungry, and we call the situation that lets them remain so a national tragedy and morally unacceptable circumstance in the richest Nation on earth. Those, I realize, are strong words. But they are also carefully chosen and in no way hyperbolic. Later I will attempt to put impartial numbers to those words, and then some humanity.

But before I do that, let me stop and offer MOWAA's sincere thanks to this Subcommittee, and in particular to you, Mr. Chairman, for your longstanding support of Senior Nutrition Programs as well as for your leadership in ensuring that these programs received increases in appropriations the past several fiscal years. We are quite mindful that the chairman's mark of the Senate version of the fiscal year 2011 bill, crafted by this Subcommittee and approved by the full Committee, contained increases of \$38 million above the fiscal year 2010 level for these programs. We are grateful for those actions at the same time that we are extremely disheartened that the final fiscal year 2011 continuing resolution did not provide for any increases.

Today Senior Nutrition Programs are struggling to maintain services; many are unable to do so and therefore are forced to reduce services. That is today, and as prices of gasoline and food continue to climb, more and more programs will find themselves in that predicament. More starkly, homebound seniors who cannot shop and prepare meals for themselves, who have no other access to nutritious food, will be forced to go without meals. The consequences of that are something for which we will all pay. I use the word "pay" both literally and figuratively. If we leave frail seniors languishing in their homes without proper nutrition, their health will inevitably fail. If they survive, they will end up hospitalized or institutionalized at a cost to the Government that far exceeds the cost of providing adequate funds to Senior Nutrition Programs to enable them to furnish seniors meals in the homes and other settings. Senior Nutrition Programs can provide meals for nearly 1 year for roughly the cost of one Medicare day in the hospital. We can quantify the savings that can accrue when seniors receive nutritious meals immediately following a hospital stay for an acute condition.

Our evidence in this regard is based on 2006 data (in 2006 dollars) from a special project that MOWAA carried out in partnership with a major national insurance company. The findings were presented in December 2006 in Washington at a Leadership Summit sponsored by AoA. Through the special partnership, Medicare Advantage patients in select markets across the United States were offered without

cost to themselves 10 meals, delivered by local Meals On Wheels programs, immediately following hospital discharge. Participation was purely voluntary. Individuals who chose to receive the service were typically sicker than those who declined it. Despite this, the insurance data show that those seniors who received meals had first month post-discharge healthcare costs on average \$1,061 lower than those who did not. The beneficial affects were also lasting. The third month after receiving those meals, the average per person savings were \$316. Individuals who did not receive meals had both more inpatient hospital days and more inpatient admissions per 1,000 than those who did receive meals. I cannot calculate the savings had meals been provided to every senior who was discharged from the hospital, or even to half of them, but I know that it is significant. According to PricewaterhouseCoopers, preventable hospital readmissions cost the Nation approximately \$25 billion each year. One out of every five Medicare patients discharged from a hospital is readmitted within 30 days at an annual cost to Medicare of \$17 billion. Given these facts, providing adequate funds for Senior Nutrition Programs can only be regarded as a strong and demonstrable value proposition. Beyond that, from a human and humane perspective, and from the perspective of the value of individuals and their liberty—principals on which this Nation was founded and for which it still stands—it is the only acceptable and right thing to do.

As you are well aware, however, the President's fiscal year 2012 budget proposes continued funding for these programs for another fiscal year at the fiscal year 2010 level. If that occurs it will not only be costly on the other side of the Federal ledger but it will also be nothing less than disastrous for seniors who are already vulnerable. So we appeal to this Subcommittee to provide substantial increases above the President's request for Title III C1 (Congregate Meals), Title III C2 (Home-Delivered Meals) and Nutrition Services Incentive Program (NSIP). We ask knowing that the fiscal context in which you are working for this fiscal year 2012 appropriation bill is extraordinarily challenging, and we ask knowing that providing increases to our programs means reducing or eliminating others. But we also ask knowing that without such increases vulnerable seniors will go hungry.

One of the great strengths of community-based Senior Nutrition Programs is that they are strong public-private partnerships that rely on the community to contribute significant financial support to augment those Federal funds furnished through this Labor, Health and Human Services, Education and Related Agencies appropriation bill. A host of partners give generously, and without them Senior Nutrition Programs could not operate. But without a strong Federal commitment in the form of adequate appropriations most Senior Nutrition Programs could not leverage these other funds effectively. In fiscal year 2009, the last year for which AoA has data, only 28.4 percent of the expenditures for Title III C2 home-delivered meals were Title III dollars. The remainder was from other sources. For Title III C1 congregate meals the Title III share was 41 percent. Funds are not the only invaluable resources that communities contribute to Senior Nutrition Programs. The programs typically rely on volunteers to perform many of the critical functions of the operation, such as meal delivery. We are proud to claim what we believe to be the largest volunteer army in the world, numbering in the neighborhood of 1.7 million individuals each year. Despite all of these assets Senior Nutrition Programs will fail to reach the most vulnerable elderly in their communities without adequate Federal financial support.

Simply put, Senior Nutrition Programs are lifelines to those men and women they serve. Regrettably they are reaching only a small proportion of the population needing services. A February 2011 Government Accountability Office (GAO) report prepared for Senator Herb Kohl paints a grim picture. The GAO (GAO-11-237) found that “. . . approximately 9 percent of an estimated 17.6 million low-income older adults received meal services like those provided by Title III programs. However, many more older adults likely needed services, but did not receive them . . . For instance, an estimated 19 percent of low-income older adults *were food insecure and about 90 percent of these individuals did not receive any meal services* [emphasis added]. Similarly approximately 17 percent of those with low incomes had two or more types of difficulties with daily activities that could make it difficult to obtain or prepare food. *An estimated 83 percent of those individuals with such difficulties did not receive meal services* [emphasis added].

As dire as this report is, we wish to point out that it undercounts the percentage of the population needing services that fail to receive them. This is due to the fact that the GAO confined their investigation to low-income seniors. Title III and NSIP funded meal programs are explicitly prohibited by the Older Americans Act (OAA) from means-testing and many individuals with incomes above the Federal poverty line receive services based on their physical condition, homebound status, social or geographic isolation and other factors that create an inability to access nutritious

food from any other source. If you factor individuals meeting these criteria into the equation, the percentage of seniors needing meal services but who do not get them will certainly increase. Surely our Federal and national commitment to our most vulnerable elders should reach more than 10 percent of those needing meals.

Given the current economic situation and the exponential growth of the aging population, if funding remains static it is unavoidable that the percentage of people needing services to whom Senior Nutrition Programs will be able to provide services will erode substantially. Sky-rocketing food and fuel prices are having a deleterious impact on programs that are dependent upon these two items. MOWAA has determined that every 1 cent increase in the price of gasoline results in a \$250,000 increase in the cost of providing services. Gasoline prices for the week of May 9, 2011 were \$1.06 higher than for the same week of 2010. This means that costs nationally of delivering services based on this factor alone increased by \$26,500,000. It is true that some, but not all, of these costs are borne by volunteers who donate the use of their vehicles, but as gas prices increase many of these individuals, a number of whom are older and on fixed incomes themselves, are either requesting reimbursement from programs or suspending their volunteer activities. When this happens, Senior Nutrition Programs often must bear the costs. The point is that factors far outside the control of Senior Nutrition Programs are increasing their costs; so flat funding will translate into a significant reduction or curtailment of nutrition services to our most vulnerable seniors.

Last year, MOWAA engaged an expert actuary to examine Federal funding for Senior Nutrition Programs for the past two decades. Looking at population data and appropriations, he determined a per capita commitment to seniors and Senior Nutrition Programs in fiscal year 1992. Then, taking into account the growth in the ages 60+ and the 85+ population and the changes in the CPI-U, he projected what the fiscal year 2012 total appropriation for Title III C1, Title III C2 and NSIP would be in fiscal year 2011 if that per capita commitment were maintained. The current year (fiscal year 2011) figure would be \$1,275,571,000 based on the 60+ population and \$1,743,182,000 based on the 85+ population. We are not asking for either of those funding levels, the latter of which be more than double the current year appropriation of \$819,474,000 for the three line items combined. But we do believe that this provides a reasonable context in which to make decisions. Surely the senior citizens of today are as valuable and deserving of life sustaining meals as those seniors of two decades ago were. Meals are not dispensable. To live and live healthily people must eat. To ensure that frail seniors do, Congress must increase funding for Senior Nutrition Programs. We respectfully request that increases of no less than your Subcommittee originally approved for fiscal year 2011, that is of at least \$38 million for Title III C combined with a commensurate increase for NSIP, should be the baseline.

In closing I would like to thank this Subcommittee again for its longstanding support, acknowledge that MOWAA understands the difficulty of your task and the boldness of our "ask" in this difficult budget year. We mean no disrespect. But part of our role, in addition to supporting our member Senior Nutrition Programs in providing meals, is to call attention to the need to afford those older adults, who contributed so much to this Nation, the respect that they are due. It is in that spirit that we make our request. As you consider it and as you make the difficult funding decisions that the Subcommittee must, we respectfully request that you think of Senior Nutrition Programs not simply as one of the hundreds of programs supported through the Labor, Health and Human Services, Education and Related Agencies appropriation bill, but instead as an essential service. For what is more essential to the sustaining of life than nutritious food and hydration? Those are the fundamental services Senior Nutrition Programs deliver.

Again, we thank you for the opportunity to present this testimony to you.

PREPARED STATEMENT OF THE MEDICAL LIBRARY ASSOCIATION AND ASSOCIATION OF
ACADEMIC HEALTH SCIENCES LIBRARIES

SUMMARY OF RECOMMENDATIONS FOR FISCAL YEAR 2011

Continue the commitment to the National Library of Medicine (NLM) by increasing funding levels to \$402 million for fiscal year 2012.

Continue to support the medical library community's role in NLM's outreach, telemedicine, disaster preparedness and health information technology initiatives and the implementation of healthcare reform.

INTRODUCTION

The Medical Library Association (MLA) and the Association of Academic Health Sciences Libraries (AAHSL) thank the Subcommittee for the opportunity to submit testimony regarding fiscal year 2012 appropriations for the National Library of Medicine (NLM), a division of the National Institutes of Health. Working in partnership with other parts of the NIH and other Federal agencies, NLM is the key link in the chain that translates biomedical research into practice, making the results of research readily available worldwide.

MLA is a nonprofit, educational organization with approximately 4,000 health sciences information professional members worldwide. Founded in 1898, MLA provides lifelong educational opportunities, supports a knowledge base of health information research, and works with a global network of partners to promote the importance of quality information for improved health to the healthcare community and the public. AAHSL is composed of the directors of 123 libraries of accredited U.S. and Canadian medical schools, and 26 associate members. AAHSL's goals are to promote excellence in academic health sciences libraries and to ensure that the next generation of health practitioners is trained in information seeking skills that enhance the quality of information delivery. Together, MLA and AAHSL address health information issues and legislative matters of importance to both our organizations.

THE IMPORTANCE OF ANNUAL FUNDING INCREASES FOR NLM

We are pleased that the fiscal year 2010 appropriations package contained funding increases for NIH and NLM which

bolstered their baseline budgets, and that the proposed fiscal year 2011 budget included increases. In today's challenging budget environment, we recognize the difficult decisions Congress faces as it seeks to improve our Nation's fiscal stability. We appreciate and thank the Subcommittee for its commitment to strengthening the NIH and NLM budget.

MLA and AAHSL believe that increased funding for NLM is essential to maximize the return on the investment in research conducted by the NIH and other organizations. By collecting, organizing, and making the results of biomedical information more accessible to other researchers, clinicians, business innovators, and the public, NLM enables such information be used more efficiently and effectively to drive innovation and improve the national's health. This role has become more important as the volume of biomedical data produced each year expands exponentially driven by the influx of data from high-throughput genome sequencing systems and genome-wide association studies. NLM plays a critical role in accelerating nationwide deployment of health information technology, including electronic health records (EHRs) by leading the development, maintenance and dissemination of key standards for health data interchange that are now required of certified EHRs. NLM also contributes to Congressional priorities related to drug safety through its efforts to expand its clinical trial registry and results database in response to recent legislation requirements, and to the nation's ability to prepare for and respond to disasters.

We encourage the Subcommittee to continue to provide meaningful annual increases for NLM in the coming years and recommend an increase to \$402 million for fiscal year 2012. Recovery funding and the fiscal year 2010 budget increases stimulated the economy and biomedical research. For NLM, Recovery Act funding allowed timely and much needed increases in support of leading edge research and training in biomedical informatics—the kinds of programs that will influence future health information technology developments. In fiscal year 2012 and beyond, it is critical to augment NLM's baseline budget to accommodate expansion of its information resources, services, and programs which must collect, organize, and make accessible rapidly expanding volumes of biomedical knowledge.

Growing Demand for NLM's Basic Services

The National Library of Medicine is the world's largest biomedical library and the source of trusted health information. Every day, medical librarians across the Nation assist clinicians, students, researchers, and the public in accessing the information they need to save lives and improve health. NLM delivers more than a trillion bytes of data to millions of users every day to help researchers advance scientific discovery and accelerate its translation into new therapies; provides health practitioners with information that improves medical care and lowers its costs; and gives the public access to resources and tools that promote wellness and disease prevention. Without NLM, our Nation's medical libraries would be unable to provide the

quality information services that our Nation's health professionals, educators, researchers and patients have come to expect.

NLM's data repositories and online integrated services such as GenBank, PubMed, and PubMed Central are helping to revolutionize medicine and advance science to the next important era which includes individualized medicine based on an individual's unique genetic differences. GenBank, with its international partners, has become the definitive source of gene sequence information and organizing, along with NLM's other genetic databases, the volumes of data that are needed to detect associations between genes and disease and translate that knowledge into better diagnosis and treatments. PubMed, with more than 20 million citations to the biomedical literature, is the world's most heavily used source of information about published results of biomedical research. Approximately 700,000 new citations are added each year, and it is searched more than 2.2 million times each day. PubMed Central, NLM's freely accessible digital repository of biomedical journal articles, has become a valuable resource for researchers, clinicians, consumers and librarians. On a typical weekday more than 420,000 users download 740,000 full-text articles. We commend the Appropriations Committee for its support of the NIH public access policy which requires all NIH-funded researchers to deposit their final, peer-reviewed manuscripts in NLM's PubMed Central database within 12 months of publication. This highly beneficial policy is improving access to timely and relevant scientific information, stimulating discovery, informing clinical care, and improving public health literacy. We ask the Committee to remain a strong voice in support of the NIH policy and to support the extension of public access policies to other Federal science and education agencies because this would bring the benefits of public access to other research disciplines and because research in other fields is increasingly relevant to biomedicine.

As the world's largest and most comprehensive medical library, NLM's traditional print and electronic collections continue to steadily increase each year. These collections stand at more than 11.4 million items—books, journals, technical reports, manuscripts, microfilms, photographs and images. By selecting, organizing and ensuring permanent access to health science information in all formats, NLM is ensuring the availability of this information for future generations, making it accessible to all Americans, irrespective of geography or ability to pay, and ensuring that each citizen can make the best, most informed decisions about their healthcare.

Clearly, NLM is a national treasure which is making a difference in patients' lives and healthcare outcomes. For example, an MLA member shared that recently a surgeon came to the library 12 minutes before surgery to find an article on the complex procedure he was about to perform. By searching NLM's PubMed/Medline database, the librarian found illustrations that guided the surgeon during surgery enabling him to save the man's foot.

ENCOURAGE NLM PARTNERSHIPS WITH THE MEDICAL LIBRARY COMMUNITY

Outreach and Education

NLM's outreach programs are of interest to both MLA and AAHSL. These activities are designed to educate medical librarians, health professionals and the general public about NLM's services and to train them in the most effective use of these services. NLM has taken a leadership role in promoting educational outreach aimed at public libraries, secondary schools, senior centers and other consumer-based settings. Furthermore, NLM's emphasis on outreach to underserved populations assists the effort to reduce health disparities among large sections of the American public. One example of NLM's leadership is the "Partners in Information Access" program which is designed to improve the access of local public health officials to information needed to prevent, identify and respond to public health threats. With nearly 6,000 members in communities across the country, the National Network of Libraries of Medicine (NNLM) is well positioned to ensure that every public health worker has electronic health information services that can protect the public's health.

NLM is also at the forefront of efforts to provide consumers with trusted, reliable health information. Its MedlinePlus system provides consumer-friendly information on more than 80 topics in English and Spanish and has become a top destination for those seeking information on the Internet, attracting more than half-million visitors per day. Librarians at Louisiana State University's Health Sciences Center Medical Library in Shreveport provide in-person support for patients and the public seeking health information and have also established "healthelinks.org", a website with information on diseases and conditions, medicines, procedures and surgical operations, lab tests, and more from NLM's MedlinePlus system. With help from Congress, NLM, NIH and the Friends of NLM launched NIH MedlinePlus Magazine in September 2006. This quarterly publication is distributed in doctors' waiting rooms

and provides the public will access to high-quality, easily understood health information. Its readership is now estimated at 5 million people nationwide and is poised to grow thanks to the launch of a Spanish/English version, NIH MedlinePlus Salud, in January 2009. NLM also continues to work with medical librarians and health professionals to encourage doctors to provide MedlinePlus “information prescriptions” to their patients, directing them to relevant information on NLM’s consumer-oriented MedlinePlus information system. This initiative also encourages genetics counselors to prescribe the use of NLM’s Genetic Home Reference website. Using NLM’s new MedlinePlus Connect utility, a growing number of clinical care organizations are implementing specific links from their electronic health record systems to relevant patient education materials in MedlinePlus, enabling them to achieve an emerging criterion for achieving meaningful use of health information technology. MedlinePlus Connect was recently named a winner in the HHS Innovates competition.

NLM also provides access to information about clinical research for a wide range of diseases. Launched in February 2000, ClinicalTrials.gov contains registration information for some 105,000 trials. The database is a free and invaluable resource for patients and families who are interested in participating in cutting-edge treatments for serious illnesses. In recent years, it has become more valuable for patients, clinicians, researchers, and others, including librarians, who help patients identify relevant trials and provide clinicians and researchers with access to information about specific products such as new drugs under study. In response to the Food and Drug Administration Amendments Act of 2007, NLM has expanded ClinicalTrials.gov to accept summary results of clinical trials, including adverse events. Such information is not available systematically from other publicly accessible resources, and all too often is not published in the scientific literature. The system currently contains results for more than 3,200 trials, and the Library receives approximately 50 new results submission each week. More than 50,000 users visit the site each day.

MLA and AAHSL applaud the success of NLM’s outreach initiatives, particularly those initiatives that reach out to the medical libraries and health consumers. We ask the Committee to encourage NLM to continue to coordinate its outreach activities with the medical library community in fiscal year 2012.

Emergency Preparedness and Response

NLM has a long history of programs and resources that support disaster preparedness and response activities. Building on its experiences in responding to Hurricane Katrina, NLM established a Disaster Information Management Research Center to collect and organize disaster-related health information, ensure effective use of libraries and librarians in disaster planning and response, and develop information services to assist responders. MLA and NLM are developing a Disaster Information Specialization (DIS) program aimed at building the capacity of librarians and other interested professionals to provide disaster-related health information outreach. Earlier this year, NLM convened a Disaster Information Outreach Symposium for information professionals across the country. This highly successful program addressed strategies for assessing and meeting the information needs of disaster managers and responders; communications, social media and disasters; using library facilities to support disaster needs during response and recovery, workforce development; disaster resources for librarians; and tools for providing disaster health information. Working with libraries and American publishers, NLM has established an Emergency Access Initiative that makes available free full-text articles from hundreds of biomedical journals and reference books for use by medical teams responding to disasters. This initiative has been activated multiple times in the last 15 months to assist relief efforts in Japan, Pakistan, and Haiti. It organized and made available health information resources relevant to the Gulf Oil spill. MLA and AAHSL see a clear role for NLM and the Nation’s health sciences libraries in disaster preparedness and response activities, and we ask the Subcommittee to support NLM’s role in this initiative which has a major objective of ensuring continuous access to health information and effective use of libraries and librarians when disasters occur.

MLA and AAHSL see a clear role for NLM and the Nation’s health sciences libraries in disaster preparedness and response activities, and we ask the Subcommittee to support NLM’s role in this initiative which has a major objective of ensuring continuous access to health information and effective use of libraries and librarians when disasters occur.

Health Information Technology and Bioinformatics

NLM has played a pivotal role in creating and nurturing the field of medical informatics which is the intersection of information science, computer science and healthcare. Health informatics tools include computers, clinical guidelines, formal medical terminologies, and information and communication systems. For nearly 35 years, NLM has supported informatics research, training and the application of advanced computing and informatics to biomedical research and healthcare delivery including a variety of telemedicine projects. Many of today's informatics leaders are graduates of NLM-funded informatics research programs at universities across the country. Many of the country's exemplary electronic and personal health record systems benefits from NLM grant support.

The importance of NLM's work in health information technology continues to grow as the Nation moves toward more interoperable health information technology systems. A leader in supporting, licensing, developing and disseminating standard clinical terminologies for free United States-wide use (e.g., SNOWMED), NLM works closely with the Office of the National Coordinator for Health Information Technology (ONCHIT) to promote the adoption of interoperable electronic records. It has developed tools to make it easier for EHR developers and users to implement accepted health data standards in their systems.

MLA and AAHSL encourage the Subcommittee to continue their strong support for NLM's medical informatics and genomic science initiatives, at a point when the linking of clinical and genetic data holds increasing promise for enhancing the diagnosis and treatment of disease. MLA and AAHSL also support health information technology initiatives in ONCHIT that build upon initiatives housed at NLM.

Building and Facility Needs

The tremendous growth in NLM's basic functions related to the acquisition, organization and preservation of its ever-expanding collection of biomedical literature, combined with its growing contributions to healthcare reform, health information technology, drug safety, and exploitation of genomic information is straining the Library's physical resources. During times of economic hardship, NLM's role becomes increasingly important and it often serves as an archive of last resort for medical libraries looking for ways to cut back and trim their own collections.

NLM now houses 1,100 staff in a facility built to accommodate 650. This increase in the volume of biomedical information and in the number of personnel has led to a serious space shortage. Digital archiving—once thought to be a solution to the problem of housing physical collections—has only added to the challenge, as materials must often be stored in multiple formats and as new digital resources consume increasing amounts of data center storage space. As a result, the space needed for computing facilities has also grown, and a new facility is urgently needed. This need has been recognized by the NLM Board of Regents as well as the Subcommittee in Senate Report 108–345 that accompanied the fiscal year 2005 appropriations bill. However, the economic challenges of the last several years have hampered movement on this project.

While Congress continues to face tremendous funding challenges in fiscal year 2012, MLA and AAHSL encourage the Subcommittee to acknowledge the need for construction of the new building to take place when the Federal budget stabilizes so that information-handling capabilities and biomedical research are not jeopardized. At a time when medical and health science libraries across the Nation face growing financial and space constraints, ensuring that NLM continues to serve as the archive of last resort for biomedical collections is critical to the medical library community and the public we serve.

Thank you again for the opportunity to present the views of the medical library community.

PREPARED STATEMENT OF THE MEHARRY MEDICAL COLLEGE

Mr. Chairman and members of the subcommittee, thank you for the opportunity to present my views before you today. I am Dr. Wayne J. Riley, President and CEO of Meharry Medical College in Nashville, Tennessee. I have previously served as vice-president and vice dean for health affairs and governmental relations and associate professor of medicine at Baylor College of Medicine in Houston, Texas and as assistant chief of medicine and a practicing general internist at Houston's Ben Taub General Hospital. In all of these roles, I have seen firsthand the importance of minority health professions institutions and the Title VII Health Professions Training programs.

Mr. Chairman, time and time again, you have encouraged your colleagues and the rest of us to take a look at our Nation and evaluate our needs over the next 10 years. I took you seriously and came here prepared to offer my best judgments. First, I want to say that it is clear that health disparities among various populations and across economic status are rampant and overwhelming. Over the next 10 years, we will need to be able to deliver more culturally relevant and culturally competent healthcare services. Bringing healthcare delivery up to this higher standard can serve as our Nation's own preventive healthcare agenda keeping us well positioned for the future.

Minority health professional institutions and the Title VII Health Professions Training programs address this critical national need. Persistent and severe staffing shortages exist in a number of the health professions, and chronic shortages exist for all of the health professions in our Nation's most medically underserved communities. Our Nation's health professions workforce does not accurately reflect the racial composition of our population. For example, African Americans represent approximately 15 percent of the U.S. population while only 2–3 percent of the Nation's healthcare workforce is African American.

There is a well established link between health disparities and a lack of access to competent healthcare in medically underserved areas. As a result, it is imperative that the Federal Government continue its commitment to minority health profession institutions and minority health professional training programs to continue to produce healthcare professionals committed to addressing this unmet need.

An October 2006 study by the Health Resources and Services Administration (HRSA), entitled "The Rationale for Diversity in the Health Professions: A Review of the Evidence" found that minority health professionals serve minority and other medically underserved populations at higher rates than non-minority professionals. The report also showed that; minority populations tend to receive better care from practitioners who represent their own race or ethnicity, and non-English speaking patients experience better care, greater comprehension, and greater likelihood of keeping follow-up appointments when they see a practitioner who speaks their language. Studies have also demonstrated that when minorities are trained in minority health profession institutions, they are significantly more likely to: (1) serve in rural and urban medically underserved areas, (2) provide care for minorities and (3) treat low-income patients.

As you are aware, Title VII Health Professions Training programs are focused on improving the quality, geographic distribution and diversity of the healthcare workforce in order to continue eliminating disparities in our Nation's healthcare system. These programs provide training for students to practice in underserved areas, cultivate interactions with faculty role models who serve in underserved areas, and provide placement and recruitment services to encourage students to work in these areas. Health professionals who spend part of their training providing care for the underserved are up to 10 times more likely to practice in underserved areas after graduation or program completion.

Institutions that cultivate minority health professionals have been particularly hard-hit as a result of the cuts to the Title VII Health Profession Training programs in fiscal year 2006 and fiscal year 2007 funding resolution passed earlier this Congress. Given their historic mission to provide academic opportunities for minority and financially disadvantaged students, and healthcare to minority and financially disadvantaged patients, minority health professions institutions operate on narrow margins. The cuts to the Title VII Health Professions Training programs amount to a loss of core funding at these institutions and have been financially devastating.

Mr. Chairman, I feel like I can speak authoritatively on this issue because I received my medical degree from Morehouse School of Medicine, a historically black medical school in Atlanta. I give credit to my career in academia, and my being here today, to Title VII Health Profession Training programs' Faculty Loan Repayment Program. Without that program, I would not be the president of my father's alma mater, Meharry Medical College, another historically black medical school dedicated to eliminating healthcare disparities through education, research and culturally relevant patient care.

Minority Centers of Excellence.—COEs focus on improving student recruitment and performance, improving curricula in cultural competence, facilitating research on minority health issues and training students to provide health services to minority individuals. COEs were first established in recognition of the contribution made by four historically black health professions institutions (the Medical and Dental Institutions at Meharry Medical College; The College of Pharmacy at Xavier University; and the School of Veterinary Medicine at Tuskegee University) to the training of minorities in the health professions. Congress later went on to authorize the es-

establishment of “Hispanic”, “Native American” and “Other” Historically black COEs. For fiscal year 2012, I recommend a funding level of \$24.602 million for COEs.

Health Careers Opportunity Program (HCOP).—HCOPs provide grants for minority and non-minority health profession institutions to support pipeline, preparatory and recruiting activities that encourage minority and economically disadvantaged students to pursue careers in the health professions. Many HCOPs partner with colleges, high schools, and even elementary schools in order to identify and nurture promising students who demonstrate that they have the talent and potential to become a health professional. Over the last three decades, HCOPs have trained approximately 30,000 health professionals including 20,000 doctors, 5,000 dentists and 3,000 public health workers. For fiscal year 12, I recommend a funding level of \$22.133 million for HCOPs.

National Institutes of Health (NIH)

Research Centers at Minority Institutions.—The Research Centers at Minority Institutions program (RCMI) at the National Center for Research Resources has a long and distinguished record of helping our institutions develop the research infrastructure necessary to be leaders in the area of health disparities research. Although NIH has received unprecedented budget increases in recent years, funding for the RCMI program has not increased by the same rate. Therefore, the funding for this important program grow at the same rate as NIH overall in fiscal year 2012.

National Institute on Minority Health and Health Disparities.—The National Institute on Minority Health and Health Disparities (NIMHD) is charged with addressing the longstanding health status gap between minority and nonminority populations. The NIMHD helps health professional institutions to narrow the health status gap by improving research capabilities through the continued development of faculty, labs, and other learning resources. The NIMHD also supports biomedical research focused on eliminating health disparities and develops a comprehensive plan for research on minority health at the NIH. Furthermore, the NIMHD provides financial support to health professions institutions that have a history and mission of serving minority and medically underserved communities. For fiscal year 2012, I recommend that this Institute’s funding grow proportionally with the funding of the NIH.

Department of Health and Human Services

Office of Minority Health: Specific programs at OMH include:

- Assisting medically underserved communities with the greatest need in solving health disparities and attracting and retaining health professionals,
- Assisting minority institutions in acquiring real property to expand their campuses and increase their capacity to train minorities for medical careers,
- Supporting conferences for high school and undergraduate students to interest them in healthcareers, and
- Supporting cooperative agreements with minority institutions for the purpose of strengthening their capacity to train more minorities in the health professions.

The OMH has the potential to play a critical role in addressing health disparities. For fiscal year 2012, I recommend a funding level of \$65 million for the OMH.

Department of Education

Strengthening Historically Black Graduate Institutions Program.—The Department of Education’s Strengthening Historically Black Graduate Institutions program (Title III, Part B, Section 326) is extremely important to MMC and other minority serving health professions institutions. The funding from this program is used to enhance educational capabilities, establish and strengthen program development offices, initiate endowment campaigns, and support numerous other institutional development activities. In fiscal year 2012, an appropriation of \$65 million is suggested to continue the vital support that this program provides to historically black graduate institutions.

Mr. Chairman, please allow me to express my appreciation to you and the members of this subcommittee. With your continued help and support, Meharry Medical College along with other minority health professions institutions and the Title VII Health Professions Training programs can help this country to overcome health and healthcare disparities. Congress must be careful not to eliminate, paralyze or stifle the institutions and programs that have been proven to work. Meharry and other minority health professions schools seek to close the ever widening health disparity gap. If this subcommittee will give us the tools, we will continue to work towards the goal of eliminating that disparity as we have done for 1876.

Thank you, Mr. Chairman, for this opportunity.

PREPARED STATEMENT OF THE MOREHOUSE SCHOOL OF MEDICINE

Mr. Chairman and members of the subcommittee, thank you for the opportunity to present my views before you today. I am Dr. John E. Maupin, President of Morehouse School of Medicine (MSM) in Atlanta, Georgia. I have previously served as President of Meharry Medical College, executive vice-president at Morehouse School of Medicine, director of a community health center in Atlanta, and deputy director of health in Baltimore, Maryland. In all of these roles, I have seen firsthand the importance of minority health professions institutions and the Title VII Health Professions Training programs.

I want to say that minority health professional institutions and the Title VII Health Professions Training programs address a critical national need. Persistent and severe staffing shortages exist in a number of the health professions, and chronic shortages exist for all of the health professions in our Nation's most medically underserved communities. Furthermore, our Nation's health professions workforce does not accurately reflect the racial composition of our population. For example while blacks represent approximately 15 percent of the U.S. population, only 2-3 percent of the Nation's health professions workforce is black. Morehouse is a private school with a very public mission of educating students from traditionally underserved communities so that they will care for the underserved. Mr. Chairman, I would like to share with you how your committee can help us continue our efforts to help provide quality health professionals and close our Nation's health disparity gap.

There is a well established link between health disparities and a lack of access to competent healthcare in medically underserved areas. As a result, it is imperative that the Federal Government continue its commitment to minority health profession institutions and minority health professional training programs to continue to produce healthcare professionals committed to addressing this unmet need.

An October 2006 study by the Health Resources and Services Administration (HRSA), entitled "The Rationale for Diversity in the Health Professions: A Review of the Evidence" found that minority health professionals serve minority and other medically underserved populations at higher rates than non-minority professionals. The report also showed that; minority populations tend to receive better care from practitioners who represent their own race or ethnicity, and non-English speaking patients experience better care, greater comprehension, and greater likelihood of keeping follow-up appointments when they see a practitioner who speaks their language. Studies have also demonstrated that when minorities are trained in minority health profession institutions, they are significantly more likely to: (1) serve in rural and urban medically underserved areas, (2) provide care for minorities and (3) treat low-income patients.

As you are aware, Title VII Health Professions Training programs are focused on improving the quality, geographic distribution and diversity of the healthcare workforce in order to continue eliminating disparities in our Nation's healthcare system. These programs provide training for students to practice in underserved areas, cultivate interactions with faculty role models who serve in underserved areas, and provide placement and recruitment services to encourage students to work in these areas. Health professionals who spend part of their training providing care for the underserved are up to 10 times more likely to practice in underserved areas after graduation or program completion.

Given the historic mission, of institutions like MSM, to provide academic opportunities for minority and financially disadvantaged students, and healthcare to minority and financially disadvantaged patients, minority health professions institutions operate on narrow margins. The slow reinvestment in the Title VII Health Professions Training programs amounts to a loss of core funding at these institutions and have been financially devastating.

Mr. Chairman, I feel like I can speak authoritatively on this issue because I received my dental degree from Meharry Medical College, a historically black medical and dental school in Nashville, Tennessee. I have seen first hand what Title VII funds have done to minority serving institutions like Morehouse and Meharry. I compare my days as a student to my days as president, without that Title VII, our institutions would not be here today. However, Mr. Chairman, since those funds have been slowly replenished, we are standing at a cross roads. This committee has the power to decide if our institutions will go forward and thrive, or if we will continue to try to just survive. We want to work with you to eliminate health disparities and produce world class professionals, but we need your assistance.

Minority Centers of Excellence: COEs focus on improving student recruitment and performance, improving curricula in cultural competence, facilitating research on minority health issues and training students to provide health services to minority

individuals. COEs were first established in recognition of the contribution made by four historically black health professions institutions (the Medical and Dental Institutions at Meharry Medical College; The College of Pharmacy at Xavier University; and the School of Veterinary Medicine at Tuskegee University) to the training of minorities in the health professions. Congress later went on to authorize the establishment of “Hispanic”, “Native American” and “Other” Historically black COEs. For fiscal year 2012, I recommend a funding level of \$24.602 million for COEs.

Health Careers Opportunity Program (HCOP): HCOPs provide grants for minority and non-minority health profession institutions to support pipeline, preparatory and recruiting activities that encourage minority and economically disadvantaged students to pursue careers in the health professions. Many HCOPs partner with colleges, high schools, and even elementary schools in order to identify and nurture promising students who demonstrate that they have the talent and potential to become a health professional. Over the last three decades, HCOPs have trained approximately 30,000 health professionals including 20,000 doctors, 5,000 dentists and 3,000 public health workers. For fiscal year 2012, I recommend a funding level of \$22.133 million for HCOPs.

National Institutes of Health (NIH)

National Institute on Minority Health and Health Disparities.—The National Institute on Minority Health and Health Disparities (NIMHD) is charged with addressing the longstanding health status gap between minority and nonminority populations. The NIMHD helps health professional institutions to narrow the health status gap by improving research capabilities through the continued development of faculty, labs, and other learning resources. The NIMHD also supports biomedical research focused on eliminating health disparities and develops a comprehensive plan for research on minority health at the NIH. Furthermore, the NIMHD provides financial support to health professions institutions that have a history and mission of serving minority and medically underserved communities through the Minority Centers of Excellence program. For fiscal year 2012, I recommend a funding increase proportional to any increase given to the NIH for the NIMHD.

Research Centers at Minority Institutions.—The Research Centers at Minority Institutions program (RCMI), currently administered at the National Center for Research Resources, has a long and distinguished record of helping our institutions develop the research infrastructure necessary to be leaders in the area of health disparities research. Although NIH has received unprecedented budget increases in recent years, funding for the RCMI program has not increased by the same rate. Therefore, the funding for this important program grow at the same rate as NIH overall in fiscal year 2012.

Department of Health and Human Services

Office of Minority Health.—Specific programs at OMH include: (1) Assisting medically underserved communities with the greatest need in solving health disparities and attracting and retaining health professionals; (2) Assisting minority institutions in acquiring real property to expand their campuses and increase their capacity to train minorities for medical careers; (3) Supporting conferences for high school and undergraduate students to interest them in healthcareers, and (4) Supporting cooperative agreements with minority institutions for the purpose of strengthening their capacity to train more minorities in the health professions. The OMH has the potential to play a critical role in addressing health disparities, and with the proper funding this role can be enhanced. For fiscal year 2012, I recommend a funding level of \$65 million for the OMH.

Department of Education

Strengthening Historically Black Graduate Institutions.—The Department of Education’s Strengthening Historically Black Graduate Institutions program (Title III, Part B, Section 326) is extremely important to MSM and other minority serving health professions institutions. The funding from this program is used to enhance educational capabilities, establish and strengthen program development offices, initiate endowment campaigns, and support numerous other institutional development activities. In fiscal year 2012, an appropriation of \$65 million is suggested to continue the vital support that this program provides to historically black graduate institutions.

Mr. Chairman, please allow me to express my appreciation to you and the members of this subcommittee. With your continued help and support, Morehouse School of Medicine along with other minority health professions institutions and the Title VII Health Professions Training programs can help this country to overcome health and healthcare disparities. Congress must be careful not to eliminate, paralyze or stifle the institutions and programs that have been proven to work. MSM and other

minority health professions schools seek to close the ever widening health disparity gap. If this subcommittee will give us the tools, we will continue to work towards the goal of eliminating that disparity as we have since our founding day.

Thank you, Mr. Chairman, and I welcome every opportunity to answer questions for your records.

PREPARED STATEMENT OF THE NATIONAL AHEC ORGANIZATION

The National AHEC Organization (NAO) is the professional organization representing Area Health Education Centers (AHECs). Our message is simple:

—The Area Health Education Center program is effective and provides vital services and national infrastructure.

—Area Health Education Centers are the workforce development, training and education machine for the Nation's healthcare safety-net programs.

AHEC is one of the Title VII Health Professions Training programs, originally authorized at the same time as the National Health Service Corps (NHSC) to create a complete mechanism to provide primary care providers for Community Health Centers (CHCs) and other direct providers of healthcare services for underserved areas and populations. The plan envisioned by creators of the legislation was that the CHCs would provide direct service. The NHSC would be the mechanism to fund the education of providers and supply providers for underserved areas through scholarship and loan repayment commitments. The AHEC program would be the mechanism to recruit providers into primary health careers, diversify the workforce, and develop a passion for service to the underserved in these future providers, i.e. Area Health Education Centers are the workforce development, training and education machine for the Nation's healthcare safety-net programs. The AHEC program is focused on improving the quality, geographic distribution and diversity of the primary care healthcare workforce and eliminating the disparities in our Nation's healthcare system.

AHECs develop and support the community based training of health professions students, particularly in rural and underserved areas. They recruit a diverse and broad range of students into health careers, and provide continuing education, library and other learning resources that improve the quality of community-based healthcare for underserved populations and areas.

The Area Health Education Center program is effective and provides vital services and national infrastructure. Nationwide, over 379,000 students have been introduced to health career opportunities, and over 33,000 mostly minority and disadvantaged high school students received more than 20 hours each of health career exposure. Over 44,000 health professions students received training at 17,530 community-based sites, and furthermore; over 482,000 health professionals received continuing education through AHECs. AHECs perform these education and training services through collaborative partnerships with Community Health Centers (CHCs) and the National Health Service Corps (NHSC), in addition to Rural Health Clinics (RHCs), Critical Access Hospitals, (CAHs), Tribal clinics and Public Health Departments.

Justification for Recommendations

Imbalances in our healthcare system result in marked inequities in access to and quality of healthcare services. This perpetuates disparities in health status and the under-representation of minority and disadvantaged individuals in the healthcare workforce. AHEC programs play a key role in correcting these inequities and strengthening the Nation's healthcare safety net.

In order to continue the progress that the Title VII Health Professions Training programs, especially AHECs, have already made toward their goal, an additional Federal investment is required. NAO recommends that the AHEC program is funded at \$75 million. Investment at this level and at this time will be the first step toward full investment at the authorized level of \$125 million.

PREPARED STATEMENT OF THE NATIONAL ALLIANCE FOR EYE AND VISION RESEARCH

EXECUTIVE SUMMARY

NAEVR requests fiscal year 2012 NIH funding at \$35 billion, which reflects a \$3 billion increase over President Obama's proposed funding level of \$32 billion. Funding at \$35 billion, which reflects NIH net funding levels in both fiscal year 2009 and fiscal year 2010, ensures it can maintain the number of multi-year investigator-

initiated research grants, the cornerstone of our Nation's biomedical research enterprise.

The vision community commends Congress for \$10.4 billion in NIH funding in the American Recovery and Reinvestment Act (ARRA), as well as fiscal year 2009 and fiscal year 2010 funding increases that enabled NIH to keep pace with biomedical inflation after 6 previous years of flat funding that resulted in a 14 percent loss of purchasing power. Fiscal year 2012 NIH funding at \$35 billion enables it to meet the expanded capacity for research—as demonstrated by the significant number of high-quality grant applications submitted in response to ARRA opportunities—and to adequately address unmet need, especially for programs of special promise that could reap substantial downstream benefits, as identified by NIH Director Francis Collins, M.D., Ph.D. in his top five priorities. As President Obama has stated repeatedly, most recently during the 2011 State of the Union Address, biomedical research has the potential to reduce healthcare costs, increase productivity, and ensure the global competitiveness of the United States.

NAEVR requests that Congress increase NEI funding above the 1.8 percent proposed by the President—even if it does not fund NIH at \$35 billion—since the proposed increase does not match biomedical inflation.

In 2009, Congress spoke volumes in passing S. Res. 209 and H. Res. 366, which designated 2010–2020 as The Decade of Vision, in which the majority of 78 million Baby Boomers will turn 65 years of age and face greatest risk of aging eye disease. This is not the time for a less-than-inflationary increase that nets a loss in the NEI's purchasing power, which eroded by 18 percent in the fiscal year 2003–fiscal year 2008 timeframe. NEI-funded research is resulting in treatments and therapies that save vision and restore sight, which can reduce healthcare costs, maintain productivity, ensure independence, and enhance quality of life.

THE BIPARTISAN NIH SUPPORT DISPLAYED AT THE SUBCOMMITTEE'S MARCH 30 HEARING WITH SECRETARY SEBELIUS DEMONSTRATES THE VALUE OF INCREASED AND TIMELY APPROPRIATIONS

NAEVR was pleased to hear the level of bipartisan support expressed for NIH at the March 30 Senate L–HHS Appropriations Subcommittee hearings with Department of Health and Human Services (DHHS) Secretary Kathleen Sebelius and was especially impressed by two sets of comments:

- Senate Ranking Member Richard Shelby (R-AL) cautioned against across-the-board cuts and urged Congress to sustain programs that are effective—where he cited NIH as “one of the most results-driven aspects of our entire Federal budget.” He added that “research conducted at NIH reduces disabilities, prolongs life, and is an essential component to the health of all Americans. NIH programs consistently meet their performance and outcomes measures, as well as achieve their overall mission.” These comments are stated so well that NAEVR will not expand upon them, other than to cite vision examples in the next sections.
- Senator Barbara Mikulski (D-MD) noted that a government shutdown, NIH cuts, or delayed appropriations, individually or in combination, will have far-reaching consequences, especially for academic Institutions across the country which receive funding.

To demonstrate that point, in late January 2011, NAEVR hosted 11 domestic and 6 international members of the Association for Research in Vision and Ophthalmology (ARVO) in Capitol Hill visits. They educated staff that a cutback to the fiscal year 2008 level would reduce NEI funding by \$30 plus million and reduce the number of grants by 43—any one of which could hold the key to saving or restoring vision. The advocates also described the impact of delayed appropriations, in terms of continuity of research and retention of trained staff. If a department does not have bridge or philanthropic funding to retain staff while awaiting full funding of awards, it will need to let staff go, and that usually means a highly trained person is lost to another area of research or an institution in another State, or even another country.

FISCAL YEAR 2012 NIH FUNDING AT \$35 BILLION ENABLES THE NEI TO BUILD UPON THE IMPRESSIVE RECORD OF BASIC AND CLINICAL/TRANSLATIONAL RESEARCH THAT MEETS NIH'S TOP FIVE PRIORITIES AND WAS FUNDED THROUGH FISCAL YEAR 2009/2010 ARRA AND INCREASED “REGULAR” APPROPRIATIONS

NEI's research addresses the preemption, prediction, and prevention of eye disease through basic, translational, epidemiological, and comparative effectiveness research which also address the top five NIH priorities, as identified by Dr. Collins:

genomics, translational research; comparative effectiveness; global health, and empowering the biomedical enterprise.

With respect to translational research, in June 2010, NEI hosted a Translational Research and Vision conference as the last of a series of NIH-campus based educational events recognizing its 40th anniversary (previous events addressed genetics/genomics, optical imaging, stem cell therapies, and the latest glaucoma research). In keynote comments, Dr. Collins recognized NEI as a leader in translational research. He specifically cited NEI's leadership in ocular genetics, noting that NEI has worked collaboratively with other NIH Institutes, especially the National Human Genome Research Institute (NHGRI) to elucidate the basis of eye disease and to develop treatments. As NEI Director Paul Sieving, M.D., Ph.D. has stated, one-quarter of all genes identified to date are associated with eye disease/visual impairment.

Dr. Collins also lauded the NEI's use of Genome-Wide Association Studies (GWAS) to determine the increased risk of developing age-related macular degeneration (AMD) from gene variants in the Complement Factor H (CFH) immune pathway, noting that "this was the first demonstration that GWAS is a useful tool to make the connection between gene variants and disease conditions." He added that, "Twenty years ago we could do little to prevent or treat AMD. Today, because of new treatments and procedures based on NIH/NEI research, 1.3 million Americans at risk for severe vision loss from AMD over the next 5 years can receive potentially sight-saving therapies."

With increased "regular" fiscal year 2009/2010 appropriations and ARRA funding, NEI has been able to build upon past research in two important areas:

Genetic Basis of AMD.—In 2010, NEI initiated the International AMD Genetics Consortium, reflecting researchers on five continents who will be sharing and analyzing GWAS results to further elucidate the genetic basis of AMD. This may lead to new diagnostics and treatments for this leading blinding eye disease, growing in incidence with the aging of the population and with potential significant costs to the Medicare program.

Treatment of Diabetic Macular Edema.—In May 2010, the NEI's Diabetic Retinopathy Clinical Research (DRCR) Network—a multi-center network dedicated to facilitating clinical research into diabetic retinopathy, diabetic macular edema, and associated conditions—reported results of a comparative effectiveness trial. The study confirmed that laser treatment for diabetic macular edema, when combined with injections of the Food and Drug Administration (FDA)-approved anti-angiogenic drug Lucentis, is more effective than laser treatment alone, the latter of which has been the standard of care for the past 25 years. With NIH's recent announcement of a new strategic plan to combat diabetes, led by the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK), this research is more important than ever within the larger context of NIH priorities. The current DRCR Network is a successor to several previous networks, all of which involved NEI–NIDDK collaboration. NEI's emphasis on diabetic retinopathy reflects the fact that it is the leading cause of vision loss in the working-age population and occurs with disproportionately greater incidence in the Hispanic population.

IF CONGRESS DOES NOT INCREASE FISCAL YEAR 2012 NIH FUNDING ABOVE THE PRESIDENT'S REQUEST, IT IS EVEN MORE VITAL TO IMPROVE UPON THE PROPOSED 1.8 PERCENT INCREASE FOR NEI

The NIH budget proposed by the administration and finalized by Congress during the second year of the congressionally designated Decade of Vision should not contain a less-than-inflationary increase for the NEI due to the enormous challenges it faces in terms of the aging population, the disproportionate incidence of eye disease in fast-growing minority populations, and the visual impact of chronic disease (e.g., diabetes). If Congress is unable to fund NIH at \$35 billion in fiscal year 2012 (NEI level of \$794.5 million) and adopts the President's proposal, the 1.8 percent increase in funding must be increased to at least an inflationary level of 2.4 percent to prevent any further erosion in NEI's purchasing power. NEI funding is an especially vital investment in the overall health, as well as the vision health, of our Nation. It can ultimately delay, save, and prevent health expenditures, especially those associated with the Medicare and Medicaid programs, and is, therefore, a cost-effective investment.

VISION LOSS IS A MAJOR PUBLIC HEALTH PROBLEM: INCREASING HEALTHCARE COSTS,
REDUCING PRODUCTIVITY, DIMINISHING LIFE QUALITY

The NEI estimates that more than 38 million Americans age 40 and older experience blindness, low vision, or an age-related eye disease such as AMD, glaucoma, diabetic retinopathy, or cataracts. This is expected to grow to more than 50 million

Americans by year 2020. The economic and societal impact of eye disease is increasing not only due to the aging population, but to its disproportionate incidence in minority populations and as a co-morbid condition of chronic disease, such as diabetes.

Although the NEI estimates that the current annual cost of vision impairment and eye disease to the United States is \$68 billion, this number does not fully quantify the impact of indirect healthcare costs, lost productivity, reduced independence, diminished quality of life, increased depression, and accelerated mortality. NEI's fiscal year 2010 baseline funding of \$707 million reflects just a little more than 1 percent of this annual costs of eye disease. The continuum of vision loss presents a major public health problem, as well as a significant financial challenge to the public and private sectors.

NAEVR URGES CONGRESS TO FUND THE NIH AT \$35 BILLION IN FISCAL YEAR 2012 WHICH WILL ENSURE THE MOMENTUM OF BREAKTHROUGH NEI-FUNDED VISION RESEARCH AND THE RETENTION OF TRAINED PERSONNEL

ABOUT NAEVR

The National Alliance for Eye and Vision Research (NAEVR) is a 501(c)4 non-profit advocacy coalition comprised of 55 professional (ophthalmology and optometry), patient and consumer, and industry organizations involved in eye and vision research. Visit NAEVR's Web site at www.eyeresearch.org.

PREPARED STATEMENT OF THE NATIONAL ALLIANCE OF STATE & TERRITORIAL AIDS DIRECTORS

The National Alliance of State & Territorial AIDS Directors (NASTAD) represents the Nation's chief State health agency staff who have programmatic responsibility for administering HIV/AIDS and viral hepatitis healthcare, prevention, education, and supportive service programs funded by State and Federal governments. On behalf of NASTAD, we urge your support for increased funding for Federal HIV/AIDS and viral hepatitis programs in the fiscal year 2012 Labor-HHS-Education Appropriations bill, and thank you for your consideration of the following critical funding needs for HIV/AIDS, viral hepatitis and STD programs in fiscal year 2012. These funding needs support activities aligned with the goals set forth in the National HIV/AIDS Strategy (NHAS)—a game-changing blueprint for tackling the Nation's HIV/AIDS epidemic.

As we approach 30 years into the HIV/AIDS epidemic, we must be mindful that HIV/AIDS is still a crisis in the United States, not just a global issue. HIV/AIDS is an emergency and while there are life-saving medications that did not exist 20 years ago, there is still no cure, and we still see new infections—about 56,000 annually. The Nation's prevention efforts must match our commitment to the care and treatment of infected individuals. First and foremost we must address the devastating impact on racial and ethnic minority communities, particularly African Americans and Latinos, as well as gay men and other men who have sex with men (MSM) of all races and ethnicities, substance users, women and youth. To be successful, we must expand outreach, scale-up and consider new and innovative approaches to arrest the epidemic here at home.

The President's fiscal year 2012 budget proposal provides increases to HIV/AIDS prevention, care and the Ryan White Program in support of the National HIV/AIDS Strategy for a total investment of \$3.5 billion. The Budget prioritizes HIV/AIDS resources within high burden communities and among high-risk groups, including MSM, African Americans and Hispanics, and realigns resources within CDC, HRSA, SAMHSA, and the Office of the Secretary to support the National HIV/AIDS Federal Implementation Plan. Additionally, the budget allows CDC and States to transfer up to 5 percent across HIV/AIDS, tuberculosis, STD and viral hepatitis programs to improve coordination and integration.

HIV/AIDS Care and Treatment Programs

The Health Resources and Services Administration (HRSA) administers the \$2.2 billion Ryan White Program that provides health and support services to more than 500,000 persons living with HIV/AIDS (PLWHA). The President's budget includes an increase of \$63 million for a total of \$2.4 billion for the entire Ryan White Program. The Budget also includes \$940 million for AIDS Drug Assistance Programs (ADAPs), an increase of \$55 million.

NASTAD requests a minimum increase of \$183 million in fiscal year 2012 for State Ryan White Part B grants compared to the President's budget of flat funding Part B at its fiscal year 2010 level of \$418.8 million and requesting a \$55 million

increase or a total of \$940 million for ADAPs. We are requesting an increase of \$77 million for the Part B Base and \$106 million or a total of \$991 million for ADAPs. ADAPs truly need an increase of \$360 million in fiscal year 2012 to maintain their programs and fill the structural deficits that have built up during the last several years. With these funds States and territories provide care, treatment and support services to PLWHA, who need access to HIV clinicians, life-saving and life-extending therapies, and a full range of support services to ensure adherence to complex treatment regimens. All States have reported to NASTAD a significant increase in the number of individuals seeking Part B Base and ADAP services.

State ADAPs provide medications to low-income uninsured or underinsured PLWHA. In fiscal year 2009, over 213,000 clients were enrolled in ADAPs nationwide. Due to many factors such as unemployment, economic challenges, increased HIV testing and linkages to care, and new HIV treatment guidelines calling for earlier therapeutic treatments, program demand has increased dramatically, and thus ADAPs are ever more in crisis. As of May 19, 2011, there 8,310 individuals are on waiting lists in 13 States to receive their life-sustaining medications through ADAP:

- Alabama: 15 individuals
- Arkansas: 59 individuals
- Florida: 3,938 individuals
- Georgia: 1,520 individuals
- Idaho: 14 individuals
- Louisiana: 696 individuals
- Montana: 26 individuals
- North Carolina: 242 individuals
- Ohio: 413 individuals
- South Carolina: 693 individuals
- Utah: 6 individuals
- Virginia: 684 individuals
- Wyoming: 4 individuals

Last year, as of April 2010, there were 10 States with less than 900 individuals on waiting lists. Thus, we have seen an over 900 percent increase in individuals on waiting lists in the last year.

HIV/AIDS Prevention and Surveillance Programs

One of the major goals of the NHAS is to lower the annual number of new infections from 56,300 to 42,225 by 2015. In order to meet this ambitious goal, NASTAD requests an increase of \$90 million above fiscal year 2011 funding levels for a total of \$555 million compared to the President's request of a \$4 million increase for State and local health department HIV prevention and surveillance cooperative agreements in order to provide comprehensive prevention programs. By providing adequate resources to State and local health departments to scale up HIV prevention and surveillance programs, we will be closer to meeting the NHAS goal of reducing new HIV infections by 25 percent by 2015. In addition, NASTAD fully supports the President's request to allocate \$30.4 million from the Prevention and Public Health Fund for HIV prevention activities consistent with the allocation of these resources in fiscal year 2010.

Of the total increase requested, NASTAD supports an increase of \$60 million above fiscal year 2011 levels compared to the President's request of a \$6.4 million increase for the HIV prevention cooperative agreements with health departments in order to scale up effective prevention programs and enable CDC to implement a new funding formula that would provide equitable funding to all jurisdictions based on disease burden without dismantling existing prevention efforts in some jurisdictions. Moreover, these additional resources will allow health departments to increase their efforts in a variety of areas such as: expanding the reach of activities targeting men who have sex with men (MSM). According to the September 2010 CDC Fact Sheet *HIV/AIDS Among Gay and Bisexual Men*, MSM account for nearly half (48 percent) of the more than 1 million people living with HIV/AIDS and account for 53 percent of new infections. Young men from racial and ethnic minority communities bear a disproportionate burden of the disease and there are more new HIV infections among young Black MSM (aged 13–29) than among any other age and racial group of MSM. Additional funding will allow health departments to continue developing and implementing innovative, cost effective and evidence-based prevention programming. Increased funding will also allow health departments to expand services to other disproportionately impacted populations including Black women, persons who inject drugs and youth. With additional funding, health departments will expand outreach, targeted and routine HIV testing, partner services and linkage to care and other evidence-based prevention interventions. Increased funding will also allow for the expansion of additional core prevention services such as partner services (the

identification, notification and counseling of partners of persons whom have tested HIV positive), capacity building and technical assistance to implement routine HIV testing and highly targeted behavior change interventions to community-based organizations and healthcare providers as well as public education campaigns to reinforce accurate, evidence-based information and begin to reduce the stigma associated with the disease.

In addition, NASTAD believes increased funding should be directed toward critical HIV surveillance efforts and requests an increase of \$30 million above fiscal year 2011 levels compared to the President's request of a decrease of nearly \$2 million. Additional resources will allow improvements in core surveillance and expand surveillance for HIV incidence, behavioral risk, and receipt of care information including CD4 and viral load reporting. HIV surveillance data are the mechanism through which the success at achieving the goals of the NHAS will be measured. The completeness of national HIV surveillance activities is critical to monitor the HIV/AIDS epidemic and to provide data for targeting with greater precision the delivery of HIV prevention, care, and treatment services.

The funding increase will also allow for the continuation of the Expanded Testing Program, Enhanced Comprehensive HIV Prevention Planning (ECHPP) and Program Collaboration and Service Integration (PCSI) activities. NASTAD supports maintaining funding at \$70 million to health departments to continue the highly successful Expanded Testing Program (ETP), which targets African Americans, Latinos, gay and bisexual men of all races and ethnicities, and persons who inject drugs. For the 30 jurisdictions currently funded for ETP, the program has been an effective way to implement routine HIV testing in clinical settings—increasing the number of people who know their HIV status and linking those with HIV to care and treatment. During the first 3 years of the program approximately 2.6 million tests were conducted with an estimated 28,000 being confirmed HIV positive. Reducing new HIV infections relies heavily on “knowing your status.” This program should be preserved with adequate funding to ensure that more individuals learn their HIV status and are linked to care.

The first step in the NHAS is to “intensify HIV prevention efforts in communities where HIV is most heavily concentrated.” In response, in August 2010, the CDC funded ECHPP. Eligible jurisdictions were awarded on September 30, 2010 with an average award of \$960,000. Through ECHPP, these highly impacted urban areas were awarded resources to test and evaluate new approaches to integrate planning, monitoring and delivering HIV prevention and care services in their specific localities. NASTAD supports continuing ECHPP funding at \$12 million in order to fund the next round of State health departments for this important activity.

NASTAD also requests continued support for Program Collaboration and Service Integration (PCSI) to enable health departments to integrate prevention services for HIV, STD, viral hepatitis, and TB at the client level. Currently six jurisdictions are funded by CDC for PCSI activities.

HIV School-based Prevention for Youth

NASTAD also supports an increase for evidence-based programs for youth funded through the CDC. An increase of \$10 million above the President's fiscal year 2012 level of \$40 million should be supported for HIV school health for a total of \$50 million. CDC currently funds HIV school health programs through the Division of Adolescent and School Health (DASH). The President's budget proposal moves HIV-specific DASH funding to the National Center for HIV/AIDS, Viral Hepatitis, STD and TB Prevention to ensure closer coordination with other HIV prevention programs, which NASTAD supports. One-third of all new infections are among young people under the age of 29, the largest share of any age group of new infections.

Viral Hepatitis Prevention Programs

NASTAD requests an increase of \$40 million for a total of \$59.8 million in fiscal year 2012 compared to the President's request of \$5.2 million for a total of \$25 million. Funding increases would go to the CDC's Division of Viral Hepatitis (DVH) to support the HHS Action Plan on Viral Hepatitis for a national testing, education and surveillance initiative as outlined in the Division's professional judgment budget submitted to Congress last year. While we are hopeful about the first-ever HHS Viral Hepatitis Action Plan, funding is needed to support increased capacity at the HHS Office of the Assistant Secretary for Health (ASH) for supporting the implementation of this plan.

We believe that testing to identify over 3 million people or 65–75 percent of chronic hepatitis B and C patients who do not know they are infected is the highest priority for reducing illness and death related to viral hepatitis. Testing must accompany education efforts to reach those already infected and at high risk of death and

of spreading the disease. Surveillance is needed to monitor disease trends and evaluate evidence-based interventions. Unlike other infectious diseases, viral hepatitis lacks a national surveillance system. Further this funding would enhance the role of Adult Viral Hepatitis Prevention Coordinators (AVHPCs) based in State health departments to implement and integrate testing, education and surveillance into the existing public health infrastructure. States and cities receive an average funding award from DVH of \$90,000, which supports a single staff position and is not sufficient for the provision of core prevention services. Therefore, NASTAD requests funding to State adult viral hepatitis prevention coordinators be increased from \$5 to \$10 million.

In addition, we encourage Congress to work with CDC to provide adequate hepatitis B vaccination through the Section 317 program as proposed in CDC's fiscal year 2012 budget. In years past, cost-savings from the Section 317 program supported an at-risk adult hepatitis B vaccine initiative with a funding high of \$20 million. While this funding went to vaccine-purchase only and not staff capacity or infrastructure, it was a highly successful initiative at administering nearly 1 million doses of vaccine. Unfortunately cost-savings for the program were expended in fiscal year 2011.

Further we encourage the utilization of health reform's Prevention and Public Health Fund to support a broad testing and screening initiative that would include neglected diseases such as viral hepatitis in order to capture patients before they progress in their liver disease and increase costs to public healthcare systems.

STD Prevention Programs

NASTAD supports an increase of \$212.7 million for a total of \$367.4 million in fiscal year 2012 compared to the President's request of a \$7 million increase for STD prevention, treatment and surveillance activities undertaken by State and local health departments. CDC's Division of STD Prevention has prioritized four disease prevention goals—Prevention of STD-related infertility, STD-related adverse pregnancy outcomes, STD-related cancers and STD-related HIV transmission. CDC estimates that 19 million new infections occur each year, almost half of them among young people ages 15 to 24. In one year, the United States may spend over \$8 billion to treat the symptoms and consequences of STDs. Untreated STDs contribute to infant mortality, infertility, and cervical cancer. Additional Federal resources are needed to reverse these alarming trends and reduce the Nation's health spending. The teen pregnancy prevention initiative should be expanded to include prevention of HIV and STDs and funded at \$20 million above the President's 2012 request of \$114.5 million. Such an increase would allow providers to serve an additional 100,000 youth.

As you contemplate the fiscal year 2012 Labor, HHS and Education Appropriations bill, we ask that you consider all of these critical funding needs. We thank the Chairman, Ranking Member and members of the Subcommittee, for their thoughtful consideration of our recommendations. Our response to the HIV, viral hepatitis and STD epidemics in the United States defines us as a society, as public health agencies, and as individuals living in this country. There is no time to waste in our Nation's fight against these infectious and often chronic diseases. The Nation's prevention efforts must match our commitment to the care and treatment of infected individuals.

PREPARED STATEMENT OF THE NATIONAL ASSOCIATION FOR PUBLIC HEALTH STATISTICS AND INFORMATION SYSTEMS

The National Association for Public Health Statistics and Information Systems (NAPHSIS) welcomes the opportunity to provide this written statement for the public record as the Labor, Health and Human Services (HHS), Education and Related Agencies Appropriations Subcommittee prepares its fiscal year 2012 appropriations legislation. NAPHSIS represents the 57 vital records jurisdictions that collect, process, and issue birth and death records in the United States and its territories, including the 50 States, New York City, the District of Columbia and the five territories. NAPHSIS coordinates and enhances the activities of the vital records jurisdictions by developing standards, promoting consistent policies, working with Federal partners, and providing technical assistance.

NAPHSIS respectfully requests that the Subcommittee provide the National Center for Health Statistics (NCHS) \$162 million, consistent with the President's budget request. This funding will enable the National Vital Statistics System to support States and territories as they implement the 2003 Standard Certificates of Birth, Death, and Fetal Deaths and move toward electronic collection of vital events data.

This infrastructure investment will address the Healthy People 2020 goal of increasing the number of States that record vital events using the latest U.S. standard certificates (PHI–10.1–10.3). Ultimately, this investment will lead to timelier, richer data that will facilitate public health planning, surveillance, service delivery, and evaluation. Specifically, such data will facilitate tracking of other Healthy People 2020 objectives in maternal, infant, and child health, cancer, diabetes, heart disease, respiratory disease, injury and prevention, and substance abuse, among others.

Collection of birth and death data through vital records is a State function and thus governed under State laws. NCHS purchases birth and death data from the States to compile national data on vital events—births, deaths, marriages, divorces, and fetal deaths. These data are used to monitor disease prevalence and our Nation's overall health status, develop programs to improve public health, and evaluate the effectiveness of those interventions. For example, birth data have been used to:

- Establish the relationship of smoking and adverse pregnancy outcomes;
- Link the incidence of major birth defects to environmental factors;
- Establish trends in teenage births;
- Determine the risks of low birth weight; and
- Measure racial disparities in pregnancy outcomes.

Just as fundamentally, death data are used to:

- Monitor the infant mortality rate as a leading international indicator of the Nation's health status;
- Track progress and regress in reducing mortality from the leading causes of death, such as heart disease, cancer, stroke, and diabetes;
- Document racial disparities; and
- Otherwise provide sound information for programmatic interventions.

Years of chronic underfunding at NCHS have threatened the collection of these important data on the national level, to the extent that in fiscal year 2007 NCHS would have been unable to collect a full 12 months of vital statistics data from States. Had the Subcommittee not intervened with a small but critical budget increase to continue vital statistics collection, the United States would have been the first nation in the industrialized world to be without a complete year's worth of vital data. Countless national programs and businesses that depend on vital events information would have been immeasurably affected.

Since that time, the Subcommittee has continually supported NCHS's vital statistics cooperative with the States. NAPHSIS and the broader public health community deeply appreciate these efforts. We are pleased that the President has once again followed the Subcommittee's lead in seeking to build a 21st century national statistical agency, requesting a \$23 million increase for NCHS in fiscal year 2012, and directing NCHS to support the modernization of the National Vital Statistics System. This funding increase will support States as they upgrade their outdated and vulnerable paper-based vital statistics systems, addressing critical needs for activities that have been on hold or curtailed because of budget constraints.

As we make significant strides in implementing and meaningfully using health information technology, it is imperative that we similarly invest in building a modern vital statistics system that monitors our citizens' health, from birth until death. The requested funding will move us toward a timelier and more comprehensive vital statistics infrastructure where all States collect the same data and all States collect these data electronically. Two forms of birth and death certificates are in use by States—the older 1989 standard certificate and the newer 2003 standard certificate. This more recent birth certificate revision includes data on insurance and access to prenatal care, labor and delivery complications, delivery methods, congenital anomalies of the newborn, maternal morbidity, mother's weight and height, breast feeding status, maternal infections, and smoking during pregnancy, among other factors. The 2003 death certificate includes data on smoking-related, pregnancy-related, and job-related deaths.

Currently, only 75 percent of the States and territories use the 2003 standard birth certificate and 65 percent have adopted the 2003 standard death certificate (see Table 1). Many States continue to rely on paper-based records, a practice which compromises the timeliness and interoperability of these data. Jurisdictions that had planned and budgeted to upgrade their certificates and systems have seen funding for these projects erode as States face severe budget shortfalls. These jurisdictions need the Federal Government's help to complete building a 21st century vital statistics system. The President's requested down payment will help in this regard, allowing all jurisdictions to implement the 2003 birth certificate and electronic birth record systems. Approximately \$30 million is needed to modernize the death statistics system; but the President's budget request is nonetheless an important first step.

TABLE 1.—JURISDICTIONS REQUIRING SUPPORT TO MODERNIZE VITAL STATISTICS SYSTEM

No 2003 Birth Certificate	No Electronic Birth Records	Incomplete Electronic Birth Records ¹	No 2003 Death Certificate	No Electronic Death Records	Incomplete Electronic Death Records ²
Total = 20 Alabama Alaska American Samoa Arizona Arkansas Connecticut Guam Louisiana Maine Massachusetts Minnesota Mississippi New Jersey Northern Mariana North Carolina Puerto Rico Virgin Islands West Virginia Virginia West Virginia Wisconsin	Total = 17 Alaska American Samoa Arizona Arkansas Connecticut Guam Louisiana Maine Massachusetts Minnesota New Jersey Northern Mariana North Carolina Puerto Rico Virgin Islands West Virginia Wisconsin	Total = 4 Alabama Hawaii Mississippi Rhode Island	Total = 19 Alabama Alaska American Samoa Colorado Guam Iowa Louisiana Maryland Massachusetts Mississippi North Carolina Northern Mariana Pennsylvania Puerto Rico Tennessee Virgin Islands Virginia West Virginia Wisconsin	Total = 24 Alaska American Samoa Arkansas Colorado Connecticut Florida Iowa Kentucky Louisiana Maine Maryland Massachusetts Mississippi Missouri New York North Carolina Oklahoma Pennsylvania Rhode Island Tennessee Virginia Washington West Virginia Wisconsin	Total = 27 Alabama Arizona Delaware Washington, DC Georgia Hawaii Idaho Illinois Indiana Michigan Minnesota Montana Nebraska Nevada New Hampshire New Jersey New Mexico New York City North Dakota Ohio Oregon South Carolina South Dakota Texas Utah Vermont Wyoming

¹ Has an electronic birth record but does not collect all 2003 data items; requires funding to modify the electronic birth record to collect the 2003 data items.² Has an electronic death record but requires funding to finish enrolling physicians and funeral directors in the system.

Source: NAPHSS Survey of Vital Statistics Jurisdictions.

The data NCHS collects are needed to track Americans' health and evaluate our progress improving it. The President's requested increase of \$23 million for NCHS and the National Vital Statistics System will move us toward a timelier and more comprehensive system where all States collect the same data and all States collect these data electronically, enabling us to better compare critical information on a local, State, regional, and national basis. Without additional funding, a potential erosion of State data infrastructure and lack of standardized data will undeniably create enormous gaps in critical public health information and may have severe and lasting consequences on our ability to appropriately assess and address critical health needs.

NAPHSIS appreciates the opportunity to submit this statement for the record and looks forward to working with the Subcommittee. If you have questions about this statement, please do not hesitate to contact NAPHSIS Executive Director, Patricia W. Potrzebowski, Ph.D., at ppotrzebowski@naphsis.org or (301) 563-6001. You may also contact our Washington representative, Emily Holubowich, at eholubowich@dc-crd.com or (202) 484-1100.

PREPARED STATEMENT OF THE NATIONAL ASSOCIATION OF COMMUNITY HEALTH CENTERS

Introduction

Chairman Harkin, Ranking Member Shelby, and Distinguished Members of the Subcommittee: My name is Dan Hawkins, and I am the Senior Vice President for Public Policy and Research at the National Association of Community Health Centers. On behalf of the 23 million patients served nationwide by health centers; 150,000 full-time health center staff; and countless volunteer board members; I would like to express my heartfelt appreciation to the Subcommittee for your support of America's healthcare safety net, and specifically of our mission to deliver affordable and accessible care to all Americans. I am pleased to have an opportunity to submit testimony for your consideration as you prepare the fiscal year 2012 Labor-Health and Human Services-Education and Related Agencies Appropriations bill.

About Community Health Centers

Health centers offer cost-effective, high-quality, and patient-directed primary and preventive care in 8,000 rural and urban underserved communities across the United States. In Iowa and Alabama, respectively, health centers deliver care to 154,020 patients in 108 communities and 315,670 patients in 140 communities.¹ By statute, health centers must be located in a medically underserved area (MUA) or serve a medically underserved population (MUP) and provide comprehensive primary care services to all community residents regardless of insurance status—offering care on a sliding fee scale. Because of this, health centers serve as the “healthcare home” for America's most vulnerable populations, including one-third of individuals living below poverty, one in seven Medicaid beneficiaries, and one in seven of America's uninsured. And nearly half of health center organizations are located in our Nation's rural areas.

Presidents of both parties and Senators on both sides of the aisle—including many members of this Subcommittee—have long-recognized the value of health centers. As a result and with bipartisan support, health centers have been on an expansion path for over a decade. Within the past 2 years, and as a result of investments this Subcommittee made through the American Recovery and Reinvestment Act, 127 new health centers opened and over 4.3 million new patients received access to care at virtually every health center in the country. I'd like to elaborate on why the Health Centers program is such a worthwhile investment that produces documented savings to the entire health system—a primary reason this program has been able to count on the Subcommittee's support for several decades.

Health centers save the country money by keeping patients out of costlier healthcare settings (like emergency departments and hospitals), coordinating care amongst providers of many health disciplines, and effectively managing chronic conditions. Medicaid beneficiaries who rely on health centers for routine care are 19 percent less likely to use the emergency department (ED) and 11 percent less likely to be hospitalized for ambulatory care-sensitive (ACS) conditions when compared to

¹ See <http://www.nachc.com/state-healthcare-data-list.cfm> for State Fact Sheets on Health Centers.

beneficiaries who see other providers.² Additionally, counties with at least one health center have 25 percent fewer ED visits for ACS conditions than counties without a health center presence.³ By providing timely and appropriate care, health centers save over \$1,200 per person per year, lowering costs across the healthcare system—from ambulatory care settings to hospital stays.⁴ All told, health centers currently generate \$24 billion in savings each year. This is all possible through an investment of just \$1.67 per patient per day.⁵

Health centers meet or exceed national practice standards for chronic condition treatment and ensure that their patients receive more recommended screening and health promotion services than patients of other providers—despite serving underserved and traditionally at-risk populations.⁶ The Institute of Medicine (IOM) and the U.S. Government Accountability Office (GAO) have recognized health centers as models for screening, diagnosing, and managing a wide array of relatively common and costly chronic conditions such as diabetes, cardiovascular disease, asthma, depression, cancer, and HIV.⁷ Specifically related to diabetes, a leading cause of death and disability, health centers significantly reduce the expected lifetime incidence of diabetes complications, including blindness, kidney failure, and certain forms of heart disease.⁸ America's health centers also play an important role in improving access to prenatal care and improving birth outcomes. Health centers have demonstrated their ability to reduce the disparity of low birth weight by at least 50 percent compared to the national average.⁹

A key driver of the success of the health center model is that each non-profit entity is locally-owned and directed by a patient majority board that ensures the health center is accountable and responsive to the needs of the community it serves. Research has demonstrated that this type of consumer participation on governing boards ensures higher quality care, lower costs of services, and better results.¹⁰ In addition to tailoring their services to make healthcare delivery individualized to unique local circumstances, health centers also have a substantial and positive economic impact on their communities. In 2009 alone, health centers generated \$20 billion in total economic benefit and created 189,158 jobs.¹¹

Funding Background

The Health Resources and Services Administration (HRSA) fiscal year 2011 spending or operating plan, pursuant to Section 1863 of Public Law 112–10, provides \$1.581 billion in discretionary funding for the Health Centers program—a reduction of \$604.4 million relative to the fiscal year 2010-enacted level of \$2.185 billion. Together with the \$1.0 billion in fiscal year 2011 funding available for health centers through the Affordable Care Act (ACA), health centers have a net increase of \$395.6 million in total programmatic funding for fiscal year 2011.

While we await word from HRSA about how available fiscal year 2011 programmatic funding will be allocated between existing and new health center efforts, we are heartened that there should be no interruption of existing health center ac-

²Falik M, et al. "Comparative Effectiveness of Health Centers as Regular Source of Care." January–March 2006 *Journal of Ambulatory Care Management* 29(1):24–35.

³Rust G, et al. "Presence of a Community Health Center and Uninsured Emergency Department Visit Rates in Rural Counties." Winter 2009 *Journal of Rural Health* 25(1):8–16.

⁴Ku L, et al. Strengthening Primary Care to Bend the Cost Curve: The Expansion of Community Health Centers Through Health Reform. Geiger Gibson/RCHN Community Health Foundation Collaborative at the George Washington University. June 30 2010. Policy Research Brief No. 19.

⁵Bureau of Primary Health Care, Health Resources and Services Administration, DHHS. 2009 Uniform Data System.

⁶Shi L, Tsai J, Higgins PC, Lebrun La. (2009). Racial/ethnic and socioeconomic disparities in access to care and quality of care for U.S. health center patients compared with non-health center patients. *Journal of Ambulatory Care Management* 32(4): 342–50. Hing E, Hooker RS, Ashman JJ. (2010). Primary Health Care in Community Health Centers and Comparison with Office-Based Practice. *Journal of Community Health*. 2010 Nov 3 epublished.

⁷U.S. General Accounting Office. (2003). Healthcare: Approaches to address racial and ethnic disparities. Publication No. GAO–03–862R. Institute of Medicine. Unequal Treatment: Confronting Racial and Ethnic Disparities in Healthcare. Washington, DC: National Academy of Sciences Press; 2003.

⁸Huang E, et al. "The Cost-effectiveness of Improving Diabetes Care in U.S. Federally Qualified Community Health Centers." 2007 *Health Services Research*, 42(6): 2174–93.

⁹Politzer R, Yoon J, Shi L, Hughes R, Regan J, and Gaston M. "Inequality in America: The Contribution of Health Centers in Reducing and Eliminating Disparities in Access to Care." 2001 *Medical Care Research and Review* 58(2):234–248.

¹⁰Crampton P, et al. "Does Community-Governed Nonprofit Primary Care Improve Access to Services?" 2005 *International Journal of Health Services* 35(3): 465–78.

¹¹NACHC, Capital Link. Community Health Centers as Leaders in the Primary Care Revolution. August 2010. www.nachc.com/research-data.cfm.

tivities, including the new centers and patients added in the past 2 years. We strongly support prioritizing fiscal year 2011 funding to maintain existing health center activities. It is worth noting, however, that most of the nearly \$400 million programmatic increase in the fiscal year 2011 CR is needed to continue ongoing operations—leaving very limited funding to support expansion efforts that would otherwise have been possible if the \$1.0 billion in new ACA resources were not being redirected to continue existing operations.

Currently, 60 million Americans lack access to a routine source of care.¹² And even with implementation of ACA, it is imperative that as more Americans become insured, they have access to care through a healthcare home in their community. Prior to the completion of fiscal year 2011 appropriations, health centers were on track to double their capacity and serve 40 million patients over the next 5 years, reaching a sizeable portion of the medically underserved individuals who would otherwise be forced to seek care in EDs, or delay care until hospitalization is the only option.

HRSA previously announced several fiscal year 2011 funding opportunities, including grants for new health centers and support for expanded capacity at virtually every existing health center nationwide. These opportunities produced: (1) over 800 applications submitted for 350 New Access Point (new health center) awards in communities not currently served by existing health centers, demonstrating the great need across the country for new centers to serve patients who most need access to primary care; and (2) nearly 1,100 health center grantee applications submitted to expand health center services to reach additional individuals in need in their current communities, adding new medical, oral, behavioral, pharmacy, and vision capacity. The reduction to the Health Center program's fiscal year 2011 discretionary funding leaves HRSA far short of the funding needed to make their previously-announced awards at this time.

Fiscal Year 2012 Funding Request

Health centers stand ready to continue working to ensure that everyone has access to primary and preventive healthcare services. In fiscal year 2012, we respectfully ask that the Subcommittee provide a discretionary funding level of no less than \$1.79 billion for the Health Centers program. This funding level, together with ACA funding available in fiscal year 2012, will allow health centers to extend cost-effective primary care over 3 million Americans this year alone. It will also allow HRSA to fund remaining and worthwhile applications that will go unfunded in fiscal year 2011, including over 200 new health center applications and funding for expanded medical, oral, behavioral, pharmacy, and vision health services at existing health centers.

Conclusion

As the Congress works to tackle our Nation's deficit, I understand Members of this Subcommittee are faced with incredibly difficult decisions about funding levels for the programs within the fiscal year 2012 Labor-Health and Human Services-Education and Related Agencies Appropriations bill. However, health centers have proven time and time again that the Federal investment in the Health Centers program is prudent—translating to improved health outcomes for our most vulnerable Americans and reduced healthcare expenditures for this Nation. I'd ask for this Subcommittee's support in continuing the bipartisan expansion of health centers in fiscal year 2012 to ensure that our shared goal of improved access to high-quality and cost-effective care is realized.

PREPARED STATEMENT OF THE NATIONAL ASSOCIATION OF COUNTY AND CITY HEALTH OFFICIALS

Summary

The National Association of County and City Health Officials (NACCHO) represents the Nation's 2,800 local health departments (LHDs). These governmental agencies work every day in their communities to protect people, prevent disease, and promote wellness. Local health departments have a unique and distinctive role and set of responsibilities in the larger health system and within every community. The Nation depends upon the capacity of local health departments to play this role well.

¹²NACHC, the Robert Graham Center, and Capital Link. Access Granted: The Primary Care Payoff. August 2007. www.nachc.com/accessreports.cfm.

The Nation's current financial challenges are compounded by those in State and local government further diminishing the ability of local health departments to measure population-wide illness, take steps to prevent disease and prolong quality of life, and to serve the public in ways others don't. Repeated rounds of budget cuts and lay-offs continue to erode local health department capacity. NACCHO surveys have found that from 2008 to 2010, local health departments have lost 29,000 jobs due to budget reductions. This represents a nearly 20 percent reduction in local public workforce. These are jobs in local communities nationwide.

On a fraying shoestring, local health departments continue to respond to an ever changing set of challenges, including ongoing public health emergency threats like floods, hurricanes, oil spills, infectious and chronic disease epidemics. The protection offered by local health departments can't be taken for granted. To help maintain the stability of LHDs, the Federal Government should invest in the following programs in fiscal year 2012 appropriations: National Public Health Improvement Initiative, Public Health Emergency Preparedness cooperative agreements, Advanced Practice Centers, Public Health Workforce Development, Chronic Disease Prevention and Health Promotion Grants, and Community Transformation Grants.

Public Health Recommendations

National Public Health Improvement Initiative

NACCHO request: \$50 million

Fiscal Year 2012 President's Budget: \$40.2 million

Fiscal Year 2010: \$50 million

The National Public Health Improvement Initiative (NPHII) increases local health departments' capability to meet national public health standards and conduct effective performance management. This initiative promotes the effective and efficient use of resources in local health departments across the country while strengthening our public health infrastructure. In addition, these funds improve public health policies and decisionmaking crucial to protecting our communities from public health threats. NPHII boosts the ability of local health departments to reengineer their systems to meet 21st century challenges including implementation of the full range of science-based approaches to improving community health. As local health departments prepare to meet newly established national accreditation standards, NACCHO recommends \$50 million in funding for fiscal year 2012 to continue to improve efficiency and effectiveness at local health departments.

Public Health Workforce Development

NACCHO request: \$73 million

Fiscal Year 2012 President's Budget: \$73 million

Fiscal Year 2010: \$38 million

The Nation suffers an acute shortage of trained public health professionals, including epidemiologists, laboratorians, public health nurses, and public health informaticians. This investment in public health education and training is essential to maintain a prepared and sustainable public health workforce. With the increasing variety and magnitude of public health threats, it is vital to train new public health staff and provide continuous education for existing staff in order to maintain and upgrade the skills needed to protect our communities. This funding also supports the Centers for Disease Control and Prevention (CDC) Prevention Corps, a workforce program to recruit and train new talent for assignments in State and local health departments. This new program will also address retention by requiring professionals to commit to a designated timeframe in State and local health departments as a condition of the fellowship. NACCHO recommends \$73 million in funding for fiscal year 2012 to bolster the public health workforce.

Emergency Preparedness Recommendations

Public Health Emergency Preparedness Cooperative Agreements

NACCHO request: \$730 million

Fiscal Year 2012 President's Budget: \$643 million

Fiscal Year 2010: \$715 million

Constant readiness for both new and emerging public health threats requires an established local public health team that can plan, train, and practice on a regular basis. Emergency response capabilities and tasks, such as distributing medical countermeasures, addressing the needs of at-risk individuals, conducting drills, and organizing collaboration among staff in public health departments, schools, businesses and with volunteers, requires continuous attention and ongoing preparation. These are not supplies purchased once and stored until needed. If a community is not prepared to respond to multiple hazards, capacity to respond will not be immediately available when disasters happen. Valuable time will be lost and people will suffer,

particularly the elderly, disabled and disenfranchised, low-income residents, vulnerable populations. The only way to ensure that local health departments and their community partners are ready to respond to emergencies is to maintain consistent funding. With this funding, local health departments can sustain their level of readiness to meet benchmarks that align with the Pandemic and All Hazards Preparedness Act.

With recent progress in nationwide preparedness, now is not the time to reduce Federal funding that helps health departments continue their progress and address new, emerging threats. Especially when local health departments are under great stress from the loss of over 29,000 jobs in the last few years, the Nation cannot afford to lose the gains made by recent Federal investment in public health. Continuous training and exercising of all health department staff so that they are all ready for the next emergency must continue. A loss of readiness is inevitable if the level of Federal investment is reduced.

The safety and well-being of America's communities is dependent on the capacity of their health departments to respond in any emergency that threatens human health, including bioterrorism, infectious disease outbreaks, nuclear emergencies and natural disasters. The CDC has explicitly adopted an "all-hazards" approach to preparedness, recognizing that the capabilities necessary to respond to differing public health threats have many common elements. Through the Public Health Emergency Preparedness cooperative agreements CDC supports State and local health departments so that they can adequately prepare for and respond to such emergencies. NACCHO recommends \$730 million in funding for fiscal year 2012 to continue to support emergency preparedness in our communities.

Advanced Practice Centers

NACCHO request: \$5.4 million

Fiscal Year 2012 President's Budget: 0

Fiscal Year 2010: \$5.4 million

The Advanced Practice Center program started as a CDC pilot project in 1999, and has since expanded to a national program. The APC program funds exemplary local health departments to be innovative leaders in public health preparedness to develop, evaluate, and promote products and resources that other local health department practitioners can use to meet the preparedness requirements expected for their organization or community. Since its inception, the APC program has created over 150 products and hosted numerous workshops, webinars, and other presentations to local health departments. NACCHO recommends level funding in fiscal year 2012 of \$5.4 million for the Advanced Practice Center program administered by CDC's Office of Public Health Preparedness and Response.

Disease Prevention Recommendations

Chronic Disease Prevention and Health Promotion Grants

NACCHO request: \$705 million

Fiscal Year 2012 President's Budget: \$705 million

Chronic diseases such as heart disease, cancer, stroke and diabetes are responsible for 7 of 10 deaths among Americans each year and account for 75 percent of healthcare spending. The President's budget consolidates several previously existing grants for disease prevention and health promotion to provide State and local health departments with greater flexibility to target funds to those diseases that most burden their jurisdictions, using the most effective strategies for the populations they serve. The program recognizes that many chronic diseases have common risk factors such as obesity and physical inactivity.

Supporting effective approaches to reducing contributing factors and therefore rates of chronic disease will not only make our communities healthier, but save money for taxpayers and the Government in the long run. NACCHO recommends \$705 million in funding for fiscal year 2012 to reduce chronic disease in our communities and looks forward to working with Congress on the array of details that will ensure successful, efficient, accountable implementation of a consolidated grant program that enables communities to address their chronic disease burden.

Community Transformation Grants

NACCHO request: \$221 million

Fiscal Year 2012 President's Budget: \$221 million

This program builds on the success of its predecessors: Healthy Communities, Racial and Ethnic Approaches to Community Health, and Communities Putting Prevention to Work. These funds are awarded on a competitive basis to State or local government agencies, territories, national networks of community based organizations, State or local nonprofit organizations and Indian tribes or tribal organizations

to reduce health disparities and leading causes of death. Communities will use these resources to invest in evidence-based approaches to creating a healthy population by promoting smoking cessation, active living, healthy eating, and prevention of injuries. NACCHO recommends an allocation process which makes these funds available to communities of all sizes. NACCHO recommends \$221 million in funding for fiscal year 2012 to continue proven approaches to protecting public health in our communities.

As the Subcommittee drafts the fiscal year 2012 Labor-Health and Human Services-Education Appropriations bill, we ask for consideration of NACCHO's recommendations for these programs that are critical to protecting people and improving the public's health. We are fully aware of the budgetary challenges facing Congress and the need to reduce deficit spending. Budgetary cuts must be made carefully to cause the least disruption to critical public health functions and protect the health of the U.S. population.

NACCHO thanks the Subcommittee members for their previous support of public health initiatives that support work in local communities and welcomes the opportunity to discuss these requests further.

PREPARED STATEMENT OF THE NATIONAL ASSOCIATION OF NUTRITION AND AGING SERVICES PROGRAMS

On behalf of NANASP, the National Association of Nutrition and Aging Services Programs, I thank you for providing an opportunity to submit testimony as you consider an fiscal year 2012 Labor-HHS and Education Appropriations bill. NANASP is a national membership organization for persons across the country working to provide older adults healthful food and nutrition through community-based services. NANASP has 14 members in Iowa and 17 members in Alabama.

I am writing today to urge you to provide a much needed increase to President Obama's fiscal year 2012 funding proposal for two major programs in the Older Americans Act: the senior nutrition programs and Community Service Employment for Older Adults.

The congregate and home-delivered (Meals on Wheels) nutrition programs and the Nutrition Services Incentive Program (NSIP) are the largest and most visible component of the Older Americans Act. Next year, the senior nutrition program celebrates its 40th anniversary of helping to keep millions of the vulnerable elderly healthy and independent in their homes and communities. This is a much more fiscally sound solution than having our seniors institutionalized because of the detrimental effects of hunger and malnutrition.

The President's budget proposes no increase for the senior nutrition programs in fiscal year 2012. This is extremely alarming as these same programs were deemed worthy of increases for the past 5 fiscal years. The need for an increase in funding for meals for our seniors remains today. According to the Administration on Aging (AoA), flat funding for the nutrition programs means that 36 million fewer home-delivered and congregate meals will be served in fiscal year 2012 compared to fiscal year 2010. These meals are especially critical for the health of the 58 percent of congregate and 60 percent of home-delivered meal participants who report that they receive the majority of their daily food intake from the nutrition program.

The second major program we ask you to consider for increased funding is the Community Service Employment for Older Adults, also known as the Senior Community Service Employment Program or SCSEP. Administered by the Labor Department, SCSEP provides part-time jobs to thousands of low-income seniors, about one-fourth of them working in senior nutrition and other programs serving the elderly. These disadvantaged and previously unemployed seniors earn the minimum wage as they re-enter the job market.

In fiscal year 2012, the President's budget proposes to reduce the number of SCSEP participants by 25 percent below the fiscal year 2008 level. SCSEP is the only Federal job training program targeted for older workers, who continue to suffer in today's economy. While the current unemployment rate among older adults is lower than among younger workers, older workers are less likely to find new employment, and when they do find new jobs, their job search has taken longer. For example, nearly 30 percent of unemployed people aged 55+ were jobless for an entire year or more, a rate that exceeds that of all other age groups. Such a drastic cut in funding would not only eliminate over 22,000 job opportunities for older workers, but also take away 12 million hours of staffing for senior nutrition and other programs serving the community.

At NANASP we always say, "It is more than just a meal." Our programs provide much needed socialization for older adults and the link between nutrition and

health is irrefutable. The senior nutrition and community service employment programs play a key role in health promotion and disease prevention. Our programs keep the very vulnerable elderly healthy, engaged, and independent and out of expensive long-term care institutions that are very costly to the Medicaid program. We hope you will strongly consider an increase in funding for the nutrition and community service employment programs in your Labor-HHS, Education Appropriations bill for fiscal year 2012.

PREPARED STATEMENT OF THE NATIONAL ASSOCIATION OF STATE COMPREHENSIVE
HEALTH INSURANCE PLANS

The National Association of State Comprehensive Health Insurance Plans (NASCHIP) appreciates the opportunity to submit testimony as you consider an fiscal year 2012 Labor-HHS and Education Appropriations bill. NASCHIP represents the State high risk pools which were established by statute initially passed 10 years before the Federal high risk pool program (PCIP) was created by the ACA, the Affordable Care Act. Our programs operate in 35 States including your States, Mr. Chairman and Mr. Shelby. We serve more than 200,000 people providing them with insurance notwithstanding their preexisting conditions. This number reflects a 7 percent increase from 2009 levels which we consider a significant indicator of the value and necessity of our programs.

We are here to urge that you support a level of \$75 million for the Federal grant program for State high risk pool programs for fiscal year 2012. This was the authorization level contained in our statute the State High-Risk Pool Funding Extension Act of 2006. This funding allows many States to provide means based premium subsidies to their citizens who might otherwise not be able to afford coverage.

We consider this level of funding the essential minimum for us to continue to do our work of providing a vital safety net to individuals who might otherwise be uninsured. For the current fiscal year, the Federal grant program for State high risk pool programs has \$55 million in available funding which represents only a fraction of the total costs of care for State high risk pools. In fact, total State pool expenses in 2009 were approximately \$2.2 billion.

We were disappointed that the President only requested \$44 million in funding for the Federal grant program for State high risk pools in his fiscal year 2012 budget proposal. It was based in part on an incorrect premise that as enrollments grow in the PCIP program it would lessen enrollment in our programs. The request also ignores the reality of increased enrollment into our programs in 2010. Only by receiving \$75 million in funding for fiscal year 2012 would we stand a chance of serving the individuals we need to serve.

The issues related to the PCIP program and either lower or higher than expected enrollments should have no bearing on the funding level we request. We have and will continue to work with administration officials to improve enrollments in PCIP as we want to see this program succeed. However, the State high risk pools serve a growing population and are in need of continued funding. We urge you to include \$75 million in your Labor-HHS and Education appropriations bill for fiscal year 2012.

PREPARED STATEMENT OF THE NATIONAL ASSOCIATION OF STATE HEAD INJURY
ADMINISTRATORS

Thank you for this opportunity to submit testimony regarding the fiscal year 2012 budget as it pertains to funding for programs authorized by the Traumatic Brain Injury (TBI) Act of 1996, as amended in 2008. The TBI Act authorizes funding to the U.S. Department of Health and Human Services (HHS) to carry out the intent of the Act through the (1) Centers for Disease Control and Prevention (CDC) for purposes of brain injury surveillance, prevention and education; and the (2) Health Resources and Services Administration (HRSA) for grants to State governmental agencies and to Protection and Advocacy Systems to improve and increase access to rehabilitation services and community services and supports for individuals with TBI and their families.

NASHIA is a nonprofit organization representing State governmental officials who administer an array of short-term and long-term rehabilitation and community services and supports for individuals with TBI and their families. These services are generally financed through an array of Federal, State and dedicated funds (State trust funds) with the HRSA Federal TBI grants used to support and improve the necessary infrastructure to support these service systems. While NASHIA is well

aware that Federal funds are becoming increasingly difficult to obtain, NASHIA is recommending increased funding for the Federal TBI Act programs because:

- The number of Americans who sustain a TBI is increasing, especially among the elderly and young children, and among our men and women in uniform as a result of the wars in Iraq and Afghanistan, while at the same time,
- States are experiencing significant budget cuts impacting rehabilitation and community services and supports for individuals with TBI, yet
- The number of States receiving grants has been reduced from 49 to 21 due to recent changes in HRSA policy and the level of appropriations to support State grant activities.

These factors, as well as the overall economy, are creating a strain on State TBI systems. As the TBI Act program is the only Federal funding to help States to better serve individuals with TBI, NASHIA recommends:

- \$10 million for the CDC programs to support TBI registries and surveillance; to develop Brain Injury Acute Care Guidelines, and to expand prevention and public education regarding injury prevention, including sports-related concussions (mild TBI);
- \$ 8 million for the HRSA Federal TBI State Grant Program to increase the number of grants to States; and
- \$ 4 million for the HRSA Federal TBI Protection & Advocacy (P&A) Systems Grant Program to increase the amount of grant awards.

HRSA FEDERAL TBI STATE GRANT PROGRAM

Since 1997, HRSA has awarded grants to 48 States, District of Columbia and one Territory to develop and improve services and systems to address the short-term and long-term needs. These grants have been time limited and are relatively small. Two years ago, HRSA increased the amount of the award from approximately \$100,000 to \$250,000 to make it more feasible for States to carry out their grant goals and the legislative intent. While this increased amount is more attractive to States, this change reduced the number of grantees from 49 to 21—less than half of the States and Territories. As a result, States that do not have Federal funding are finding it increasingly more difficult to sustain their previous efforts, let alone expand and improve, due to other budget constraints in their States.

Over the course of the grant program, States, depending on individual State needs, have developed State plans for improving service delivery; information and referral systems; service coordination systems; outreach and screening among unidentified populations such as children, victims of domestic violence, and veterans; and training programs for direct care workers and other staff. States have also conducted public awareness and educational activities that have helped States to leverage and coordinate funding in order to maximize resources to the benefit of individuals with TBI.

In keeping with the HRSA Federal TBI State Grant Program most States have identified a lead State agency responsible for providing and coordinating services and an advisory board to plan and coordinate public policies to better serve individuals who frequently needs assistance from multiple agencies and funding streams in order to address the complexity of their needs.

STATE COLLABORATIVE EFFORTS TO ADDRESS THE NEEDS OF VETERANS

The HRSA grant funding has been used to address the needs of returning service members and veterans with TBI and their families. Since service members and veterans first began to return from Iraq and Afghanistan, States have been contacted by families and returning servicemembers, especially those who served in the National Guard and Reserves, to obtain community resources in order to return to work, home and community.

NASHIA and some individual States have reached out to U.S. Department of Veterans Affairs (VA), particularly staff from individual Polytrauma Centers, to promote collaboration in order to better understand VA benefits for veterans that may be seeking State services, and for VA to understand what is available in the communities. In addition, some States have added representatives from VA, National Guard and Reserves, State Veterans Affairs, and/or veterans organizations to serve on their State advisory board in order to improve communications and policies across these programs.

THE INCIDENCE AND PREVALENCE OF TBI IS ON THE RISE

CDC released new data last year showing that the incidence and prevalence of TBI in the United States is on the rise. CDC reported that each year, an estimated 1.7 million people sustain a TBI. Of that amount: 52,000 die; 275,000 are hospital-

ized; and 1.365 million (nearly 80 percent) are treated and released from an emergency department. TBI is a contributing factor to a third (30.5 percent) of all injury-related deaths in the United States. About 75 percent of TBIs that occur each year are concussions or other forms of mild TBI. The number of people with TBI who are not seen in an emergency department or who receive no care is unknown.” (www.cdc.gov/TraumaticBrainInjury/statistics.html)

The data collected by CDC relies heavily on State data, gathered through State registries and hospital discharge data. These numbers do not include the veterans who sustained TBIs in Iraq or Afghanistan and now use private or State funded resources for care, or undiagnosed TBIs.

ABOUT STATE RESOURCES AND SERVICES

Since the 1980s, States have developed services and supports largely in response to families who often seek help in crisis situations, such as loss of job due to TBI; or out of control behaviors or substance abuse that may result in family violence or dangerous situations to self and others; and the need for overall help in providing care to their family members who have extensive medical, behavioral and cognitive problems. A critical service that States provide is service coordination to help coordinate and maximize resources and supports for individuals with TBI and their families.

Over the past 25 years, States have developed service delivery systems that generally offer information and referral, service coordination, rehabilitation, in-home support, personal care, counseling, transportation, housing, vocational and other support services for persons with TBI and their families. These services are funded by State appropriations, designated funding (trust funds), Medicaid and Rehabilitation Act programs and are administered by programs located in the State public health, Vocational Rehabilitation, mental health, Medicaid, developmental disabilities, education or social services agencies.

Approximately half of all States have a dedicated funding mechanism, mainly through traffic related fines, and about half of all States also administer a Medicaid Home and Community-Based Services (HCBS) Waiver for individuals with brain injury who are Medicaid eligible. Individuals with TBI are also served in other State waiver programs designed for physical disabilities, developmental disabilities, elderly and other populations. Some States have the advantage of both waiver and trust fund programs, in addition to other State and Federal resources.

As private insurance generally does not provide for extended rehabilitation and long-term care, supports and services, most long-term services and supports for persons with TBI are administered by the States. These programs are funded mainly through the shared Federal/State Medicaid Home and Community-based Services Waivers (HCBS) program and Medicaid State Plan services, such as personal assistance, nursing homes and in-home care.

Medicaid HCBS Waivers for Individuals with TBI have grown significantly in recent years, doubling from 5,400 individuals served in 2002 to 11,214 in 2006, at a cost of \$155 million in 2002 to \$327 million in 2006 (Kaiser Commission on Medicaid and the Uninsured (2007, December); Medicaid Home and Community-Based Service Programs: Data Update, The Henry J. Kaiser Family Foundation, Washington, DC).

Without appropriate services and supports, individuals with TBI may become homeless, or inappropriately placed in institutional settings or end up in State or local Correctional facilities due to their cognitive and behavioral disabilities. A recent report issued by the Centers for Disease Control and Prevention (CDC) cited other jail and prison studies indicating that 25–87 percent of inmates report having experienced a TBI as compared to 8.5 percent in a general population reporting a history of TBI.

ABOUT NASHIA

The mission of NASHIA is to assist State government in promoting partnerships and building systems to meet the needs of individuals with brain injury and their families. Since 1990, NASHIA has held an annual State-of-the-States conference, and has served as a resource to State TBI program managers. NASHIA also maintains a website (www.nashia.org) containing State program contacts and other resources. NASHIA members include State officials administering public TBI programs and services, and associate members who are professionals, provider agencies, State affiliates of the Brain Injury Association of America (BIAA), family members and individuals with brain injury.

Should you wish additional information on State services and resources, or other information, please do not hesitate to contact Rebecca Wolfkiel, Governmental Con-

sultant at 202-480-8901 (office) or rwolfkiel@ridgepolicygroup.com. You may also contact Susan L. Vaughn, Director of Public Policy, at 573-636-6946 or publicpolicy@nashia.org or William A.B. Ditto, Chair of the Public Policy Committee, at williamabditto@aol.com.

Thank you.

PREPARED STATEMENT OF THE NATIONAL ASSOCIATION OF WORKFORCE BOARDS

Thank you for the opportunity to comment on the Administration's proposed 2012 budget for the Department of Labor. The National Association of Workforce Boards (NAWB) is a member association, which represents a majority of the 575 local employer-led Workforce Investment Boards and their nearly 13,000 employer member volunteers.

We write in support of the Administration's fiscal year 2012 overall appropriations request for the Training and Employment Services account under the Department of Labor. Adequate funding for the public workforce system has never been more critical. While the worst of the economic downturn seems behind us, one-stop centers across the Nation continue to deal with large numbers of unemployed individuals who seek advice about career options and whose skills need upgraded. In short, our employment crisis is not expected to ease in the foreseeable future.

The annual Economic Report of the President indicated that unemployment would remain above 8 percent through 2012. In April of this year the rate stood at 9 percent. Federal Reserve Chairman Ben S. Bernanke said the unemployment rate is likely to remain high "for some time" even after the biggest 2-month drop in the jobless rate since 1958.

Mr. Bernanke appearing before the House Budget Committee in February 2011, said that while the declines in the jobless rate in December and January "do provide some grounds for optimism," he cautioned that "with output growth likely to be moderate for a while and with employers reportedly still reluctant to add to their payrolls, it will be several years before the unemployment rate has returned to a more normal level."

Workforce Investment Act programs have been on the front lines of assisting job seekers impacted by the recession. Over the past year, Title I of the Workforce Investment Act (WIA) system has seen over 8 million American workers turn to it for help in navigating the labor market in search of jobs and/or the training individuals need to be competitive in their labor market. This continues the trend of an over 234 percent increase in the numbers of people who have sought assistance over the last two reporting years.

Despite a ratio of four/five job seekers nationally for every available job, over 4 million were helped back into the labor force. In short, those who received WIA services were likely to find jobs with the likelihood increasing the higher the service level. Information for the quarter ending September 30, 2010 shows the following results:

Performance Results

Workforce Investment Act Adult Program

- Entered Employment Rate 53.1 percent
- Employment Retention Rate 75.3 percent
- Average 6 months Earnings \$13,482

Workforce Investment Act Dislocated Worker Program

- Entered Employment Rate 50.3 percent
- Employment Retention Rate 79 percent
- Average 6 months Earnings \$17,227

Workforce Investment Act Youth Program

- Placement in Employment or Education rate 59.5 percent
- Attainment of Literacy and Numeracy gains 49.5 percent

The ability of the public workforce system to maintain this level of success on behalf of job seekers and employers seeking skilled workers is incumbent upon the continuation of adequate funding. We encourage the Subcommittee to fund WIA formula programs at a minimum at the administration's request levels, as we expect to continue to face the challenges brought about by high unemployment for the foreseeable future.

Program Funding

We applaud the Administration's proposal for a Workforce Innovation Fund. We believe that the State and local workforce boards have developed a host of promising practices since WIA was enacted in 1998, particularly in helping address the large numbers of persons dislocated during this recession or shut-out of the labor market

due to a lack of appropriate skills. The Workforce Innovation Fund will allow local areas to engage with community partners and quickly scale effective practices on behalf of jobseekers in need.

However, we strongly urge the Subcommittee to fully fund the administration's request for WIA formula programs before allocating funding for the Workforce Innovation Fund, as these formula funds are essential to our ability to provide services to job seekers at the local level around the Nation.

The protection of the WIA formula programs to support the locally delivered services is critical as the system continues to deal with large numbers of individuals seeking work. The Continuing Resolution passed in April contained budget reductions that are already having the impact of local areas having to close and consolidate local career one-stop centers.

Policy Riders

NAWB would strongly encourage the committee to continue the policy riders that prohibit the re-designation of local areas or changes to the definition of administrative costs until WIA is reauthorized. There have been instances where there has been arbitrary action to reconfigure local areas and NAWB believes these riders will prevent any State v. local conflict until reauthorization.

We urge the Subcommittee to continue to provide the support necessary for the workforce system to help our jobseekers retool for employment in high demand sectors and maintain our global competitiveness.

Summer Youth employment

While our testimony is focused on fiscal year 2012 funding, we would be remiss if we did not express our support for summer youth funding. Youth unemployment remains at all-time highs. The unemployment rate in April 2011 was listed as 9 percent for the total civilian labor force, but for youth the rate is over 24 percent for 16–19 year olds. In summer 2009 utilizing ARRA funding for WIA Youth programs, 313,000 young people had a summer job. Youth reported to us that their wages provided much needed income to the household for basic needs of their family and for the expenses in returning to school. Lack of youth funds imperils business finding job-ready youth to fill their employment needs as the “boomer” generation begins to retire. Serving youth that are at-risk and/or school drop-outs with the level of service needed requires intense intervention that combines academic, as well as, experiential learning techniques. The summer youth employment project allowed the system to provide youth practical work experience that reinforced classroom academics. Without it, employers in the private sector become the work-ready trainers; training that we have reason to believe employers are ill-prepared and/or unwilling to provide.

We understand these budget times, but would hope that at some point the Congress would take-up the issue of youth unemployment and we are prepared to assure Congress that any additional funding for WIA Youth programs would allow us to better address the crisis we are facing in youth employment.

Thank you for the opportunity to testify.

PREPARED STATEMENT OF THE NATIONAL COALITION FOR CANCER SURVIVORSHIP

It is my pleasure to submit this statement regarding fiscal year 2012 funding for the National Institutes of Health (NIH) and the Centers for Disease Control and Prevention (CDC) on behalf of the National Coalition for Cancer Survivorship (NCCS) and the 12 million cancer survivors living in the United States. NCCS advocates for quality healthcare for survivors of all forms of cancer, and we believe the Federal Government should play a strong leadership role, through basic and clinical cancer research and delivery of survivorship services, to boost the quality of cancer care from diagnosis and for the balance of life. These research and survivorship programs should be conducted in partnership with private sector organizations.

In this statement, NCCS will focus on the need for a balanced program of basic, translational, and clinical research at the National Institutes of Health (NIH) and the National Cancer Institute (NCI) as well as the urgent need for Centers for Disease Control and Prevention (CDC) leadership to strengthen educational and informational services for survivors and improve access to cancer screening for the medically underserved.

Two recent reports—the Annual Report to the Nation on the Status of Cancer, 1975–2007, Featuring Tumors of the Brain and Other Nervous System and the Morbidity and Mortality Weekly Report of March 11, 2011, reporting on the number of cancer survivors in 2007—provide a compelling portrait of the progress the Nation has made in the fight against cancer, the work still to be done, and the pressing

needs of millions of cancer survivors who are still in active treatment or living as long-term survivors.

The Annual Report notes that the incidence of cancer is decreasing; the decrease is statistically significant for women although not for men, because of a recent increase in prostate cancer incidence. The cancer death rates are decreasing for both sexes. The decreases in incidence and mortality are attributed to progress in cancer prevention, early detection, and treatment. Despite the overall progress, there are increasing incidence rates for some cancers and low survival for certain forms of cancer. For example, pediatric cancer incidence is increasing, although death rates are down. The survival from melanoma, pancreatic cancer, liver cancer, and many forms of malignant brain tumors remains much too short.

Those who do survive cancer experience a myriad of late and long-term effects. In the editorial note accompanying the Morbidity and Mortality Weekly Report that found almost 12 million American cancer survivors, CDC stressed the need for more research to identify those cancer survivors at risk of recurrence, second cancers, and the late effects of cancer and its treatment. CDC also recommended that special attention be paid to the burden of survivorship for the medically underserved and the older cancer survivor.

Recommendations for Fiscal Year 2012 Funding

NCCS recommends smart, effective, and aggressive Federal investments in initiatives to improve the quality of care and quality of life for cancer survivors. We recommend:

- A strong and sustained investment in NIH and NCI in fiscal year 2012 to support basic, translational, and clinical research aimed at answering fundamental questions about cancer, advancing new and improved cancer treatments, identifying the side effects of cancer treatments, and strengthening interventions for the late and long term effects of cancer and treatment. No reductions should be made in NIH funding in fiscal year 2012, in order to prevent interruption of both basic and clinical studies and to sustain the progress in cancer treatment that we are making through research.
- Steady progress in the overhaul of the NCI clinical trials system. The Institute of Medicine (IOM) has outlined a plan for modernizing the clinical trials system and eliminating inefficiencies, and NCI leaders have taken steps to implement the IOM recommendations. We urge completion of this reform effort, to guarantee that patients are willing to enroll in clinical research studies because they know they will be studies of high quality investigating important issues and treatments. An improved system will also ensure that research studies are efficiently completed and questions related to new treatments are answered without delay.
- A strong investment in survivorship research that will discover those at risk of late and long-term effects from cancer and treatment and appropriate interventions for those individuals.
- A sustained commitment to basic research aimed at detecting subtypes of cancer and contributing to the development of targeted, or personalized, cancer therapies.
- Maintenance of the Federal cancer screening programs—including the breast and cervical cancer screening program and the colorectal cancer screening program—in a manner that will support services to medically underserved individuals and ensure early detection and diagnosis. The proposal to create a block grant of chronic disease programs should not include the screening programs, which do not lend themselves to effective administration through a block grant.
- A strong program of education and information regarding survivorship services for the 12 million cancer survivors living in the United States. CDC has provided grant funding to support a survivorship resource center, and we urge that steps be taken to ensure that the services offered through the center reflect the latest knowledge about the problems of survivors and the most appropriate interventions. Moreover, special populations, including the medically underserved and the elderly, should be provided adequate and appropriate information and services.

Federal research and survivorship programs have yielded better treatments and enhanced quality of life for millions of American cancer patients. These programs should be sustained through continued Federal support so that the needs of a growing population of cancer survivors can be met.

PREPARED STATEMENT OF THE NATIONAL COALITION FOR OSTEOPOROSIS AND
RELATED BONE DISEASES

The National Coalition for Osteoporosis and Related Bone Diseases (Bone Coalition) would like to take this opportunity to thank you all for your continued visionary support of the National Institutes of Health—the Nation's biomedical research agency. Because of your past efforts and your appreciation of the potential and value of medical research, new scientific opportunities are being pursued that hold potential for better diagnosis, treatment, prevention and eventually cures for diseases such as osteoporosis, osteogenesis imperfecta, Paget's disease of bone, and a wide range of rare bone diseases.

Recommendation.—The National Coalition for Osteoporosis and Related Bone Diseases joins with hundreds of health and medical organizations of the Ad Hoc Group for Medical Research Funding in urging the Committee to provide an appropriation of \$35 billion in fiscal year 2012 for the National Institutes of Health. This increase will create substantial opportunities for scientific and health advances, while also providing key economic scientific support in communities across the Nation.

Organized in the early 1990s, the Bone Coalition is dedicated to increasing Federal research funding for bone diseases through advocacy and education. Five leading national bone disease groups comprise the Bone Coalition: two professional societies, the American Academy of Orthopaedic Surgeons and the American Society for Bone and Mineral Research; and three voluntary health organizations, the National Osteoporosis Foundation, the Osteogenesis Imperfecta Foundation, and the Paget Foundation for Paget's Disease of Bone and Related Disorders.

Osteoporosis and related bone diseases are omnipresent—affecting people of all ages, ethnicities, and gender. These diseases profoundly alter the quality of life and constitute a tremendous burden to patients, society and the economy—causing loss of independence, disability, pain and death. The annual direct and indirect costs for bone and joint healthcare are \$849 billion—7.7 percent of the U.S. gross domestic product.

—Osteoporosis is a bone-thinning disease in which the skeleton can become so fragile that the slightest movement, even a cough or a sneeze can cause a bone to fracture. About 10 million Americans already have the disease, and another 34 million people have low bone density, which puts them at risk for osteoporosis and bone fractures. According to estimated figures, osteoporosis was responsible for more than 2 million fractures in 2005, including hip, spine, wrist, and other fractures. The number of fractures due to osteoporosis is expected to rise to more than 3 million by 2025. Approximately 1 in 2 women and up to 1 in 4 men over age 50 will break a bone because of osteoporosis, and an average of 24 percent of hip fracture patients age 50 and older will die in the year following their fracture. Individuals with certain diseases are at higher risk of developing osteoporosis. For example: diabetes patients are at increased risk for developing an osteoporosis-related fracture; cancer patients are at increased risk because many cancer therapies, such as chemotherapy and corticosteroids, have direct negative effects on bone; and certain cancers, including prostate and breast cancer, may be treated with hormonal therapy, which can cause bone loss.

—Osteogenesis imperfecta, or “brittle bone disease,” is an inherited genetic disorder characterized by fragile bones which fracture easily, often from no apparent cause. A severely affected child begins fracturing before birth. Hundreds of fractures can be experienced in a lifetime, as well as hearing loss, short stature, skeletal deformities, weak muscles and respiratory difficulties. As many as 50,000 Americans may be affected by this disease.

—Paget's disease of bone is a geriatric disorder that results in enlarged and deformed bones in one or more parts of the body. Excessive bone breakdown and formation can result in bone which is structurally disorganized, resulting in an overall decrease in bone strength and an increase in susceptibility to bowing of limbs and fractures. Pain is the most common symptom. Other complications include arthritis and hearing loss if Paget's disease affects the skull. Paget's disease of bone affects 1½ to 8 percent of older adults depending on a person's age and where he or she lives. Approximately 700,000 Americans over the age of 60 are affected.

Past investments in NIH by your Committee have paid dividends for patients in the many advances in the bone research field, and these investments have had significant impact on public health. In just one example, researchers have recently discovered that bisphosphonate drugs commonly prescribed for osteoporosis and Paget's disease significantly reduce death rates by preventing fractures among older adults, producing mortality rates five times lower than those over 60 taking no bone medi-

cations. Years of basic research by NIH established the scientific foundation for development of this type of medication now producing significant results.

And while progress to date has clearly been impressive, there is still no cure for osteoporosis, osteogenesis imperfecta, Paget's disease or numerous other diseases and conditions that affect the skeleton. Depending on the disease, the opportunity to build on recent discoveries for new treatments, cures and preventive measures has never been greater. With that in mind, the Coalition has identified the following areas where further intensive investigation is warranted:

Office of the NIH Director.—The Coalition urges the Director to work with all relevant Institutes to enhance interdisciplinary research leading to targeted therapies for improving the density, quality and strength of bone for all Americans. More scientific knowledge is needed in a number of key areas involving bone and muscle, fat, and the central nervous system. Research is also urgently needed to improve the identification of populations who might require earlier treatment because they are at risk of rapid bone loss due to a wide range of conditions or diseases: obesity, diabetes, chronic renal failure, cancer, HIV, conditions that affect absorption of nutrients or medications, or addiction to tobacco, alcohol or other opiates. The Coalition encourages NIH to develop a plan to expand genetics and other research on rare bone diseases, including: osteogenesis imperfecta, Paget's disease of bone, fibrous dysplasia, osteopetrosis, fibrous ossificans progressiva, melorheostosis, X-linked hypophosphatemic rickets, multiple hereditary exostoses, multiple osteochondroma, Gorham's disease, and lymphangiomatosis.

National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS).—The Coalition urges support for research into the pathophysiology of bone loss in diverse populations. The information gained will be critical in developing targeted therapies to reduce fractures and improve bone density, quality and strength. Efforts are needed to determine appropriate levels of calcium and vitamin D for bone health at different life stages. Research is also needed in assessing bone microarchitecture and remodeling rates for determining fracture risk, anabolic approaches to increase bone mass, novel molecular and cell-based therapies for bone and cartilage regeneration, and discerning the clinical utility of new, non-invasive bone imaging techniques to measure bone architecture and fragility. Support for studies on the molecular basis of bone diseases such as Paget's disease, osteogenesis imperfecta and other rare bone diseases should also be a priority.

National Cancer Institute (NCI).—The Coalition urges investigations on how to repair bone defects caused by cancer cells. Translational research is also needed to understand the impact of metastasis on the biomechanical properties of bone and the mechanisms by which bone marrow and tumor derived cells can influence metastatic growth, survival and therapeutic resistance.

National Institute on Aging (NIA).—The Coalition encourages research to better define the causes of age-related bone loss and fractures, reduced physical performance and frailty, including identifying epigenetic changes, with the aim of translating basic and animal studies into new therapeutic approaches. Critical research is also needed on changes in bone structure and strength with aging, and the relationship of age-related changes in other organ systems. The prevention and treatment of other metabolic bone diseases, including osteogenesis imperfecta, glucocorticoid-induced osteoporosis, and bone loss due to kidney disease should also be priority research areas.

National Institute of Child Health and Human Development (NICHD).—The Coalition urges research in the new, emerging field of metabolic disease and bone in children and adolescents, especially childhood obesity, anorexia nervosa and other eating disorders. Research is also needed on what the optimal Vitamin D levels should be in children to achieve bone health, and the implications of chronic or seasonal Vitamin D deficiency to the growing skeleton. Development and testing of therapies and bone building drugs for pediatric patients are also a pressing clinical need. The committee is encouraged by results thus far from the Bone Mineral Density in Childhood Study (BMDCS) that will serve as a valuable resource for clinicians and investigators to assess bone deficits in children and risk factors for impaired bone health. However the committee is concerned that without further funding to continue the study, there will be inadequate data on bone development in adolescents and different ethnic groups. Therefore the committee encourages NIH to extend the study and to explore research that will lead to better understanding and prevention of osteopenia and osteoporosis.

National Institute of Dental and Craniofacial Research (NIDCR).—The Coalition urges continued research support on the effects of systemic bone active therapeutics on the craniofacial skeleton, including factors predisposing individuals to osteonecrosis of the jaw, as well as new approaches to facilitate bone regeneration.

The Coalition commends NIDCR for its longstanding intramural program on fibrous dysplasia.

National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK).—The Coalition encourages support for research on the relationship between Vitamin D and morbidity and mortality in chronic kidney disease. Research is also needed on the value of anti-resorptive therapies, the link between renal insufficiency and diabetic bone disease, the differences in calcification of blood vessels, the mechanisms of metastasis of renal cell carcinoma, and diseases that occurs in patients with end stage chronic renal disease on hemodialysis.

National Institute of Neurological Disorders and Stroke (NINDS).—The Coalition encourages research support into the pathophysiology of spinal cord, brachial plexus, and peripheral nerve injuries in order to develop targeted therapies to improve neural regeneration and functional recovery.

National Institute of Biomedical Imaging and Bioengineering (NIBIB).—The Coalition encourages critical research to advance our ability to treat bone diseases and disorders through bone imaging, as well as managing the loss of bone and soft tissue associated with trauma by advancing tissue engineering strategies to replace and regenerate bone and soft tissue.

Centers for Disease Control and Prevention

On another front, prevention is of major concern to the Coalition. As the population ages and the ranks of senior citizen Baby Boomers expand, the annual cost of acute and long-term care for osteoporosis, alone, is projected to increase dramatically from \$19 billion annually to more than \$25 billion by 2025. Without significant intervention now, chronic diseases such as osteoporosis will overwhelm efforts to contain healthcare costs. Thanks to medical research better diagnosis, prevention and screening strategies and treatment therapeutics are now available to address the growing problem of osteoporosis.

The recent HHS report, “Enhancing Use of Clinical Preventive Services Among Older Adults: Closing the Gap,” calls attention to the potential of preventive measures for osteoporosis. The report shows new data outlining critical gaps with a high percentage of women on Medicare reporting never having received osteoporosis screenings. Yet, as the report states, studies have proven that osteoporosis screening using hip scans and follow-up management can reduce hip fractures by 36 percent. In 1999 alone, Medicare spent more than \$8 billion to treat injuries to seniors, with fractures accounting for two-thirds of the spending.

The Coalition, therefore, urges the Director of the Centers for Disease Control to develop an education and outreach plan in consultation with the patient and medical community to begin laying the ground work to address osteoporosis on a public health basis.

PREPARED STATEMENT OF THE NATIONAL CONSUMER LAW CENTER

The Federal Low Income Home Energy Assistance Program (LIHEAP)¹ is the cornerstone of Government efforts to help needy seniors and families stay warm and avoid hypothermia in the winter, as well as stay cool and avoid heat stress (even death) in the summer. LIHEAP is an important safety net program for low-income, unemployed and underemployed families struggling in this economy. The demand for LIHEAP assistance remains at record high levels for a third year in a row. In fiscal year 2011, the program is expected to help an estimated 9 million low-income households afford their energy bills. The unemployment and poverty forecasts for fiscal year 2012 indicate that the number of struggling households will also remain at these high levels. In light of the crucial safety net function of this program in protecting the health and well-being of low-income seniors, the disabled, and families with very young children, we respectfully request that LIHEAP be fully funded at its authorized level of \$5.1 billion for fiscal year 2012 and that advance funding of \$5.1 billion be provided for the program in fiscal year 2013.

LIHEAP Provides Critical Help With Home Energy Bills for The Large Number of Low-Income Households Struggling to Move Forward in These Difficult Economic Times

Funding LIHEAP at \$5.1 billion for the regular program in fiscal year 2011 is essential in light of the sharp increase in poverty and unemployment and the steady

¹ 42 U.S.C. §§ 8621 et seq.

climb in home energy prices in recent years.² One indicator of the growing need for energy assistance is the growing number of disconnections. In States like Ohio that track utility disconnections, the disconnection numbers for gas and electric residential customers have increased by 23.9 percent over 5 years. For the year ending December 2010, there were 452,221 disconnections. For the year ending December 2006, there were 364,912 gas and electric disconnections. For the years ending December 2009, 2008, and 2007, there were 476,490, 424,952, and 424,411 gas and electric disconnections respectively. LIHEAP helps bring the cost of essential heating and cooling within reach for an estimated 9 million low-income households and helps keep these struggling households connected to essential utility service.

The demand for LIHEAP increases when residential home energy prices increase, such as the fly up in home heating oil and propane in the winter of fiscal year 2011.³ Since the winter of 2005–2006, energy costs have increased from \$1,337 to \$2,291 for households heating with home heating oil; \$1,275 to \$2,040 for households heating with propane, and \$723 to \$947 for households heating with electricity. Households heating with natural gas have experience more moderate increases from \$813 to \$990. Home energy is also more expensive during prolonged periods of extreme temperatures because households use more fuel to keep the home at safe temperatures. For example, a colder than normal winter can result in higher heating bills than in years past. The third variable that drives up the demand for LIHEAP is the number of households that are struggling with unemployment, underemployment and the number of households in poverty.

Unfortunately, the number of households that are struggling to make ends meet remains very high. According a Pew Fiscal Analysis Initiative report, as of December 2010, 30 percent of the 14 million unemployed have been unemployed for a year or longer.⁴ While long-term unemployment has affected all age groups, older workers have been hit particularly hard by this downturn.⁵ CBO's budget and economic outlook report projects that unemployment will be 8.2 percent by the fourth quarter in fiscal year 2012, far from the 5.3 percent that CBO estimates is the natural rate of unemployment.⁶ A recent Brookings Center on Children & Families analysis looks at the correlation between unemployment rates and poverty rates and estimates that the poverty rate will increase to over 15 percent in 2012.⁷ Thus indications are that the demand for LIHEAP in fiscal year 2012 will remain very strong as this program helps struggling households in a number of ways. LIHEAP protects the health and safety of the frail elderly, the very young and those with chronic health conditions, such as diabetes, that increase susceptibility to temperature extremes. LIHEAP assistance also helps keep families together by keeping homes habitable during the bitter cold winter and sweltering summers.

LIHEAP Is a Critical Safety Net Program for the Elderly, the Disabled and Households With Young Children

Dire Choices and Dire Consequences.—Recent national studies have documented the dire choices low-income households face when energy bills are unaffordable. Because adequate heating and cooling are tied to the habitability of the home, low-income families will go to great lengths to pay their energy bills. Low-income households faced with unaffordable energy bills cut back on necessities such as food, medicine and medical care.⁸ The U.S. Department of Agriculture has released a study that shows the connection between low-income households, especially those with elderly persons, experiencing very low food security and heating and cooling seasons

²See, Chad Stone, Arloc Sherman and Hannah Shaw, *Administration's Rational For Severe Cut in Low-Income Home Energy Assistance is Weak*, Figure 2 (CBPP calculation of winter fuel price index from EIA) Center on Budget and Policy Priorities, February 18, 2011.

³Id.

⁴Pew Economic Policy Group Fiscal Analysis Initiative, *Addendum: A Year or More: The High Cost of Long-Term Unemployment*, January 27, 2011.

⁵Id. ("More than 40 percent of unemployed workers older than 55 have been out of work for at least a year").

⁶CBO, *The Budget and Economic Outlook: Fiscal Years 2011 to 2021*, Summary (January 2011 at Summary Table 2).

⁷Emily Monea and Isabel Sawhill, *An Update to "Simulating the Effect of the 'Great Recession' on Poverty"*, Brookings Center on Children and Families (September 16, 2010).

⁸See e.g., National Energy Assistance Directors' Association, *2008 National Energy Assistance Survey*, Tables in section IV, G and H (April 2009) (to pay their energy bills, 32 percent of LIHEAP recipients went without food, 42 percent went without medical or dental care, 38 percent did not fill or took less than the full dose of a prescribed medicine, 15 percent got a payday loan). Available at <http://www.neada.org/communications/press/2009-04-28.htm>.

when energy bills are high.⁹ A pediatric study in Boston documented an increase in the number of extremely low weight children, age 6 to 24 months, in the 3 months following the coldest months, when compared to the rest of the year.¹⁰ Clearly, families are going without food during the winter to pay their heating bills, and their children fail to thrive and grow. A 2007 Colorado study found that the second leading cause of homelessness for families with children is the inability to pay for home energy.¹¹

When people are unable to afford paying their home energy bills, dangerous and even fatal results occur. In the winter, families resort to using unsafe heating sources, such as space heaters, ovens and burners, all of which are fire hazards. Space heaters pose 3 to 4 times more risk for fire and 18 to 25 times more risk for death than central heating. In 2007, space heaters accounted for 17 percent of home fires and 20 percent of home fire deaths.¹² In the summer, the inability to keep the home cool can be lethal, especially to seniors. According to the CDC, older adults, young children and persons with chronic medical conditions are particularly susceptible to heat-related illness and are at a high risk of heat-related death. The CDC reports that 3,442 deaths resulted from exposure to extreme heat during 1999–2003.¹³ The CDC also notes that air-conditioning is the number one protective factor against heat-related illness and death.¹⁴ LIHEAP assistance helps these vulnerable seniors, young children and medically vulnerable persons keep their homes at safe temperatures during the winter and summer and also funds low-income weatherization work to make homes more energy efficient.

LIHEAP is an administratively efficient and effective targeted health and safety program that works to bring fuel costs within a manageable range for vulnerable low-income seniors, the disabled and families with young children. LIHEAP must be fully funded at its authorized level of \$5.1 billion in fiscal year 2012 in light of unaffordable, but essential heating and cooling needs of millions of struggling households due to the record high unemployment levels.

In addition, fiscal year 2013 advance funding would facilitate the efficient administration of the State LIHEAP programs. Advance funding provides certainty of funding levels to States to set income guidelines and benefit levels before the start of the heating season. States can also better plan the components of their program year (e.g., amounts set aside for heating, cooling and emergency assistance, weatherization, self-sufficiency and leveraging activities) if there is forward funding. Forward funding is critical to LIHEAP running smoothly.

PREPARED STATEMENT OF THE NATIONAL COUNCIL OF SOCIAL SECURITY
MANAGEMENT ASSOCIATIONS

On behalf of the National Council of Social Security Management Associations (NCSSMA), thank you for the opportunity to submit our written testimony on the fiscal year 2012 funding for the Social Security Administration (SSA) to the Subcommittee. I am the President of NCSSMA and have been the District Manager of the Social Security office in Newburgh, New York for 10 years. I have worked for the Social Security Administration for 31 years, with 27 years in management.

NCSSMA is a membership organization of nearly 3,400 SSA managers and supervisors who provide leadership in 1,299 community based Field Offices and Tele-service Centers throughout the country. We are the front-line service providers for SSA in communities all over the Nation. We are also the Federal employees with whom many of your staff members work to resolve problems and issues for your con-

⁹Mark Nord and Linda S. Kantor, *Seasonal Variation in Food Insecurity Is Associated with Heating and Cooling Costs Among Low-Income Elderly Americans*, *The Journal of Nutrition*, 136 (Nov. 2006) 2939–2944.

¹⁰Deborah A. Frank, MD et al., *Heat or Eat: The Low Income Home Energy Assistance Program and Nutritional and Health Risks Among Children Less Than 3 years of Age*, *AAP Pediatrics* v.118, no.5 (Nov. 2006) e1293–e1302. See also, Child Health Impact Working Group, *Unhealthy Consequences: Energy Costs and Child Health: A Child Health Impact Assessment Of Energy Costs And The Low Income Home Energy Assistance Program* (Boston: Nov. 2006) and the Testimony of Dr. Frank Before the Senate Committee on Health, Education, Labor and Pensions Subcommittee on Children and Families (March 5, 2008).

¹¹Colorado Interagency Council on Homelessness, *Colorado Statewide Homeless Count Summer, 2006*, research conducted by University of Colorado at Denver and Health Sciences Center (Feb. 2007).

¹²John R. Hall, Jr., *Home Fires Involving Heating Equipment* (Jan. 2010) at ix and 33. Also, 40 percent of home space heater fires involve devices coded as stoves.

¹³CDC, “Heat-Related Deaths—United States, 1999–2003” *MMWR Weekly*, July 28, 2006.

¹⁴CDC, “Extreme Heat: A Prevention Guide to Promote Your Personal Health and Safety” available at http://emergency.cdc.gov/disasters/extremeheat/heat_guide.asp.

stituents who receive Social Security retirement, survivors and disability benefits, and Supplemental Security Income. Since the founding of our organization over 41 years ago, NCSSMA has considered our top priority to be a strong and stable Social Security Administration, one that delivers quality and prompt locally delivered service to the American public. We also consider it a top priority to be good stewards of the taxpayers' moneys.

Appropriations to the Social Security Administration are an excellent investment and return on taxpayer dollars. We are very appreciative of the support for SSA funding the Subcommittee has provided in recent years. The additional funding SSA received in fiscal years 2008–2010 helped significantly to prevent workloads from spiraling out of control and assisted with improving service to the American public.

NCSSMA strongly supports the President's fiscal year 2012 budget request for SSA. The total SSA budget request is \$12.667 billion, which includes \$12.522 billion in administrative funding through the Limitation on Administrative Expenses (LAE) account. We respectfully request that the Subcommittee provides at the least the President's full budget request for SSA in fiscal year 2012. Full funding of this request is critical to maintain staffing in SSA's front-line components, cover inflationary increases, continue efforts to reduce hearing and disability backlogs, and increase deficit-reducing program integrity work.

Current State of SSA Operations

NCSSMA has critical concerns about the dramatic growth in SSA workloads, and the need to receive necessary funding to maintain service levels vital to 60 million Americans. Despite agency strategic planning, expansion of online services, significant productivity gains, and the best efforts of management and employees, SSA is still faced with many challenges to providing the service that the American public has earned and deserves.

Over the last 7 years, SSA has experienced a dramatic increase in Retirement, Survivor, Dependent, Disability, and Supplementary Security Income (SSI) claims. The additional claims receipts are driven by the initial wave of the nearly 80 million baby boomers who will be filing for Social Security benefits by 2030—an average of 10,000 per day! Concurrently, there has been a surge in claims filed due to poor economic conditions and rising unemployment levels.

The need for resources in SSA Field Offices is critical to process these additional claims and provide other vital services to the American public. Field Offices are responsible for processing 2.4 million SSI redeterminations in fiscal year 2011, a 100 percent increase compared to fiscal year 2008. Nationally, visitors to Field Offices increased from 41.9 million in fiscal year 2007 to 45.4 million in fiscal year 2010. SSA is also experiencing unprecedented telephone call volumes, and in fiscal year 2010, SSA completed 67 million transactions over the 800 number network—the most ever. In addition to the transactions over the 800 number network, NCSSMA estimates that Field Offices receive 32 million public telephone contacts annually.

SSA Funding for Fiscal Year 2011

NCSSMA strongly supported the President's fiscal year 2011 budget request of \$12.379 billion for SSA's administrative expenses. Much of this increase was needed to cover inflationary costs for fixed expenses. Funding at this level would have assured that SSA could meet its public service obligations. Despite SSA's enormous challenges, with the Federal deficit concerns, attaining this level of funding was not possible. SSA's fiscal year 2011 appropriation for administrative funding through the LAE account was \$10.7755 billion, which is \$25 million below the fiscal year 2010 enacted level and \$275 million was rescinded from SSA's Carryover Information Technology funds.

Inadequate funding of SSA in fiscal year 2011 and additional rescissions will have major repercussions for SSA including a hiring freeze, reduction of overtime, and postponements of initiatives to improve efficiency. Reducing resources at the same time SSA workloads are increasing is a prescription for making a very productive agency that efficiently uses the taxpayers' moneys into one with significant service delays and backlogs. Service deterioration and backlogs resulting from inadequate fiscal year 2011 funding levels will have a collateral negative impact on fiscal year 2012.

Field Office Service Delivery Challenges

SSA Field Offices are experiencing tremendous stress because of increased workloads and additional visitors. The effect of funding SSA in fiscal year 2011 below fiscal year 2010 levels exacerbates the situation and has already had a significant impact on local Field Offices around the country.

- Frontline feedback from our busiest urban offices indicates that some have seen their visitor traffic explode with overflowing reception areas and increased waiting times.
- Most of SSA has been under a hiring freeze because of the current funding situation. A hiring freeze for all of fiscal year 2011 could result in a loss of over 2,500 SSA Federal employees.
- A November 2010, Office of the Inspector General (OIG) Report, “Threats against SSA employees or Property,” indicates, “SSA has experienced a dramatic increase in the number of reported threats against its employees or property. The number of threats . . . increased by more than 50 percent in fiscal year 2009 and by more than 60 percent in fiscal year 2010.”
- SSA projects 50 percent of its employees, including 66 percent of supervisors, will be eligible to retire by fiscal year 2018. Serious concerns exist about SSA’s ability to sustain service levels with the tremendous loss of institutional knowledge from front-line personnel.
- Geographical staffing disparities will occur with attrition leaving some offices significantly understaffed. This is problematic for rural SSA Field Offices, whose customers often live vast distances away, may have no Internet service, and lack access to public transportation.

SSA Online eServices to Assist with Service Delivery Challenges

The expansion of services available to the American public via the Internet has helped to alleviate the number of visitors and telephone calls to SSA. However, the Internet is not keeping pace with the increasing demand for service. High-volume transactions, such as Social Security cards and benefit verifications are not available on the Internet, or are only being used to a limited degree. This represents over 40 percent of the 45.4 million visitors to SSA Field Offices.

NCSSMA believes that SSA must be properly funded in fiscal year 2012 and beyond so that it may continue to invest in improved user-friendly online services to allow more online transactions. If individuals were able to successfully transact their request for services online, this would result in fewer contacts with Field Offices, improved efficiencies, and better public service.

Disability Workload Processes

Nationwide, over 3.2 million new disability claims were filed and sent to State Disability Determination Services in fiscal year 2010. This surge of increased claims has created backlogs. At the end of fiscal year 2010, the number of pending initial disability claims was at an all-time high of 824,192 cases—a 46 percent increase from the end of fiscal year 2008. SSA’s largest backlogs are hearings, appealing initial disability decisions processed by the Office of Disability Adjudication and Review. Hearing receipts continue to rise, and through April 2011, 734,666 hearings were pending which is over 29,000 more hearings than at the end of fiscal year 2010.

Despite these unprecedented challenges, SSA continues to make progress. In March 2011, the average processing time for a hearing was 359 days, the lowest level since December 2003. Unfortunately, the number of claims and hearings pending is still not acceptable to Americans who need Social Security to support their families. Progress was undermined by the fiscal year 2011 budget impasse, resulting in the suspension of opening eight planned Hearing Offices in Alabama, California, Indiana, Michigan, Minnesota, Montana, New York, and Texas. This significantly threatens to prevent SSA from eliminating the hearings backlog by fiscal year 2013.

It is important to understand that annual appropriated funding levels for SSA have a critical impact on the hearings backlog. One of the most significant reasons for the increase in the hearings backlog was the significant underfunding of SSA from fiscal year 2004 through fiscal year 2007.

President’s Proposed Fiscal Year 2012 SSA Budget

NCSSMA strongly supports the President’s fiscal year 2012 budget request for SSA and requests that Congress provide full funding to sustain the momentum achieved to allow the agency to:

- Reduce the initial disability claims backlog to 632,000 by processing over 3 million claims;
- Conduct disability hearings for 822,500 cases and reduce the waiting time for a hearing decision below a year for the first time in a decade;
- Reduce pending hearings to 597,000 from the fiscal year 2010 level of 705,367; and
- Complete additional program integrity workloads yielding nearly \$9.3 billion in savings over 10 years, including Medicare and Medicaid savings—process

592,000 medical Continuing Disability Reviews (CDRs) and 2.6 million SSI redeterminations.

SSA issues \$800 billion in benefit payments annually to 60 million people and the agency takes its stewardship responsibilities seriously. The fiscal year 2012 budget request includes \$938 million dedicated to program integrity. Investment in program integrity reviews saves taxpayer dollars and is fiscally prudent in reducing the Federal budget and deficit.

—CDRs determine whether an individual is still disabled, or if benefits should be ceased because of medical improvement. SSA has accumulated a backlog of nearly 1.5 million CDRs. Medical CDRs yield \$10 in lifetime program savings for every \$1 spent.

—SSI redeterminations review nonmedical factors of eligibility, such as income and resources, to identify payment errors. SSI redeterminations yield a return on investment of \$7 in program savings over 10 years for each \$1 spent, including Medicaid savings accruals.

NCSSMA recommends consideration of legislative proposals included in the fiscal year 2012 budget request, which can improve the effective administration of the Social Security program, with minimal effect on program dollars. We believe these proposals have the potential to reduce operational costs and increase administrative efficiency. This includes enacting the Work Incentives Simplification Pilot, requiring quarterly reporting of wages, workers compensation automatic reporting, and developing an automated system to report state and local pensions.

Conclusion

NCSSMA recognizes in the current budget environment that it will be difficult to provide adequate funding for SSA. However, Social Security is one of the most successful Government programs in the world and touches the lives of nearly every American family. We are a very productive agency and a key component of the Nation's economic safety net for the aged and disabled, but sufficient resources are necessary. A strong Social Security program equates to a strong America and it must be maintained as such for future generations.

NCSSMA sincerely appreciates the Subcommittee's interest in the vital services Social Security provides, and your ongoing support to ensure SSA has the resources necessary to serve the American public. We respectfully request your support of full funding of the President's fiscal year 2012 budget request on behalf of our agency and the American public we serve. We remain confident increased investments in SSA will benefit our entire Nation.

On behalf of NCSSMA members nationwide, thank you for the opportunity to submit this written testimony. We respectfully ask that you consider our comments, and would appreciate any assistance you can provide in ensuring the American public receives the critical and necessary service they deserve from the Social Security Administration.

PREPARED STATEMENT OF THE NATIONAL HEAD START ASSOCIATION

Chairman Harkin, Ranking Member Shelby, and Members of the Subcommittee, thank you for allowing the National Head Start Association (NHSA) to submit written testimony in support of funding for Head Start and Early Head Start. As the Head Start community's voice, NHSA believes that Head Start centers nationwide need the resources necessary to provide quality school readiness opportunities for young children and their families. The essence of Head Start is a national commitment to provide critical early education, health, nutrition, child care, parent involvement and family support services in return for a lifelong measurable impact on the low-income children and families enrolled in Head Start. Today, as our Nation's children face greater obstacles than ever before, there is a significant need to prepare the next generation for success in school and later in life, and Head Start has a proven track record of accomplishing this. The Head Start community is pleased to offer the following recommendation to Congress as it begins its consideration of fiscal year 2012 funding levels.

NHSA is grateful that the President and Congress made a solid commitment to quality early childhood education in the fiscal year 2011 Continuing Resolution by providing the funds necessary to at least maintain services for children currently served by Head Start and Early Head Start programs across the country. Quality early education prepares the Nation's youngest children for a lifetime of learning. In fact, studies show that for every \$1 invested in a Head Start child, society earns at least \$7 back through increased earnings, employment, and family stability; and decreased welfare dependency, crime costs, grade repetition, and special education.

NHSA supports President Obama's fiscal year 2012 budget request for \$8.1 billion for Head Start and Early Head Start. These funds will enable Head Start and Early Head Start centers to continue to serve the entire, increasingly vulnerable Head Start community for an additional school year, and complete some necessary program improvements both to ensure accountability and quality, as well as meet the requirements of the 2007 Head Start Reauthorization Act.

Increased Needs of an Increased At-Risk Population

One of Head Start's greatest challenges is an increasingly needy population—both among those served and those eligible for service. Today more than one in five children are born into poverty—less than \$22,050 per year for a family of four. In many areas, Head Start directors are seeing a rapid increase of homeless families/children enrolled. The Administration's request aims to address some of this growing need by allocating a significant portion of the additional funds to increasing the number of available Migrant and Seasonal, and American Indian and Alaskan Native spaces.

Though funding for Head Start has increased in recent budget years, the cost of serving families has risen at a much faster pace. When surveyed, a full 83 percent of Head Start centers reported that their costs have increased just over the past year—in fact, 25 percent of those who responded report that their fixed costs, including maintenance, transportation, and insurance, have increased by more than 11 percent over the last 12 months. This puts many local centers in the awkward position of choosing between serving fewer children and families better and according to the statutory quality standards, or serving as many as possible with perhaps lesser quality.

Additionally, Head Start and Early Head Start centers often do not have adequate resources during the enrollment process to perform a comprehensive needs assessment on all potential enrollees. Specifically, targeted funds would enable center directors to coordinate more fully with families before enrollment to determine their needs and match those needs with the capacity of the center, and work with partner organizations that may be better equipped to handle special issues. In Kansas City, Kansas, the Project EAGLE Community Programs has implemented a sort of "community triage" system, whereby families are assessed more fully, and dollars are spent much more wisely. This approach may also enable many more at-risk families that were previously on Head Start waiting lists to receive assistance from a multitude of partnering organizations—placing perhaps a higher income, yet still impoverished family to a more fitting type of service provider and providing a waiting list slot for a needier family.

Though Head Start and Early Head Start centers are able to accept a limited number of children from families with incomes slightly above the poverty threshold (up to 130 percent, or \$29,055 for a family of four) and are required to accept children with special needs, the Head Start community shares a commitment to identifying and targeting resources, especially in these economic circumstances, to the absolute neediest of families. Additional program funds to enable better monitoring, needs-assessments, and collaboration will assist Head Start providers in meeting this goal.

Necessary Accountability Improvements

Head Start and Early Head Start directors are also eager for the Administration on Children and Families to fully implement the quality improvement provisions included in the 2007 Head Start Reauthorization. The law put in place new minimum education requirements for Head Start and Early Head Start teachers and caretakers. Though employing highly qualified individuals is a goal shared by the National Head Start Association, the education requirements necessitate a higher salary range in many areas to attract and keep these highly educated professionals, putting a strain on the administrative budgets of Head Start and Early Head Start Centers. Head Start directors, when surveyed, report that they are having difficulty competing with other educational entities in their services areas; in many cases, they cannot match the salaries provided to qualified individuals in the K–12 system or in other private pre-schools.

One of the most anticipated provisions yet to be implemented will require Head Start grantees designated as low-performing to compete for continuation of their grant. This competition is an enormous undertaking for the Office of Head Start and will certainly require additional funds to design, fully staff, and execute.

However, the law also enables the creation of rigorous performance standards for each Head Start and Early Head Start center. These have not yet been publicly drafted or finalized, though the Head Start community is eager to work with Office of Head Start to inform the effective design and implementation of these perform-

ance standards. Further, we hope that the centers can be evaluated against these new standards, particularly as they relate to the impending recompetition/redesignation. We very much hope that Congress includes report language directing the Administration to ensure that Head Start and Early Head Start grantees are given the opportunity to realign and monitor themselves against the full set of new performance standards before being judged as to whether they will be subject to a recompetition/redesignation. This will ensure that all grantees, in all areas, are judged on consistent standards in competitions going forward.

Maintenance of Quality

Lastly, the National Head Start Association supports the Administration's proposal to provide \$202 million for Training and Technical Assistance Activities. Within those funds, we suggest that Congress direct the Administration to continue supporting the 10 Centers of Excellence in Early Childhood that were named last year—in the following localities: Greensburg, Pennsylvania; Baltimore, Maryland; Mount Vernon, Ohio; Houghton, Michigan; Owensboro, Kentucky; Morganton, North Carolina; Birmingham, Alabama; Denver, Colorado; Albuquerque, New Mexico; and Dunkirk, New York. Head Start directors very much value the advice of fellow practitioners, and the resources and tools these Centers have designed and provided to the Head Start community are considered effective, well-designed, and serve as models for other Head Start and Early Head Start programs to emulate. Their innovative practices and collaborative community approaches will be in more demand as practitioners adjust to the requirements of the 2007 law.

Head Start Works

Since 1965, Head Start (and now Early Head Start as well) has been providing a proven, evidence-based comprehensive program to prepare at-risk children and families for a stable, successful life. Head Start improves the odds and the options for at-risk kids for a lifetime. Kids that have been through Head Start and Early Head Start are healthier, more academically accomplished, more likely to be employed, commit fewer crimes, and contribute more to society. Head Start is a smart investment—one of the smartest and most effective we make. Study after study has demonstrated that Head Start has yielded a benefit-cost ratio as large as \$7 to \$1.¹

Head Start saves our hard-earned tax dollars by decreasing the need for children to receive special education services in elementary schools.² For example, data analysis of a recent Montgomery County Public Schools evaluation found that a MCPS child receiving full-day Head Start services requires 62 percent fewer special education services and saves taxpayers \$10,100 per child annually.³ States can save \$29,000 per year for each prisoner that they incarcerate because Head Start children are 12 percent less likely to have been charged with a crime.⁴

Head Start families with increased health literacy experience immediate healthcare benefits, including lower Medicaid costs—on average \$232 lower per family. The program has also reduced mortality rates for 5- to 9-year olds by as much as 50 percent.⁵ Studies have shown that the program reduces healthcare costs for employers and individuals because Head Start children are less obese,⁶ 8 percent more likely to be immunized,⁷ and 19 to 25 percent less likely to smoke as an adult.⁸

And these benefits last a lifetime. Head Start produces measurable, long-term results such as school-readiness, increased high school graduation rates, and reduced

¹Ludwig, J. and Phillips, D. (2007). The Benefits and Costs of Head Start. Social Policy Report. 21 (3: 4); Meier, J. (2003, June 20). Interim Report. Kindergarten Readiness Study: Head Start Success. Preschool Service Department, San Bernardino County, California.

²Barnett, W. (2002, September 13). The Battle Over Head Start: What the Research Shows. Presentation at a Science and Public Policy Briefing Sponsored by the Federation of Behavioral, Psychological, and Cognitive Sciences.

³NHSA Public Policy and Research Department analysis of data from a Montgomery County Public Schools evaluation. See Zhao, H. & Modarresi, S. (2010, April). Evaluating lasting effects of full-day prekindergarten program on school readiness, academic performance, and special education services. Office of Shared Accountability, Montgomery County Public Schools.

⁴Reuters. (2009, March). Cost of locking up Americans too high: Pew study; Garces, E., Thomas, D. and Currie, J. (2002, September). Longer-term effects of Head Start. American Economic Review, 92 (4): 999–1012.

⁵Ludwig, J. and Phillips, D. (2007) Does Head Start improve children's life chances? Evidence from a regression discontinuity design. The Quarterly Journal of Economics, 122 (1): 159–208.

⁶Frisvold, D. (2006, February). Head Start participation and childhood obesity. Vanderbilt University Working Paper No. 06-WG01.

⁷Currie, J. and Thomas, D. (1995, June). Does Head Start Make a Difference? The American Economic Review, 85 (3): 360.

⁸Anderson, K.H., Foster, J.E., & Frisvold, D.E. (2009). Investing in health: The long-term impact of Head Start on smoking. Economic Inquiry, 48 (3), 587–602.

needs for special education. And the more than 27 million Head Start graduates are working every day in our communities to make our country and our economy strong.

The Head Start community understands the budgetary pressures the Federal Government is facing and while reductions in early childhood education may produce short-term savings, as a Nation we cannot afford the lasting impact such cuts would impose on our most vulnerable children today and on our children's futures. The research shows that the "achievement gap" is apparent as early as the age of 18 months—we will spend substantially more downstream if these same young people are not prepared to graduate high-school, attend college and lead prosperous lives. We urge the Subcommittee to fully fund the President's budget request of \$8.1 billion for Head Start and Early Head Start in fiscal year 2012.

Thank you for your time and consideration.

PREPARED STATEMENT OF THE NATIONAL HEALTH COUNCIL

The National Health Council (NHC) is the only organization of its kind that brings together all segments of the healthcare community to provide a united voice for the more than 133 million people with chronic diseases and disabilities and their family caregivers. Made up of more than 100 national health-related organizations and businesses, its core membership includes approximately 50 of the Nation's leading patient advocacy groups, which control its governance. Other members include professional societies and membership associations, nonprofit organizations with an interest in health, and major pharmaceutical, medical device, biotechnology, and insurance companies.

The NHC is well aware of the challenging fiscal environment facing the Subcommittee—indeed the entire country. We recognize that Federal resources must be carefully targeted to ensure that such investments produce the greatest good for the American people. This will involve very tough decisions on healthcare priorities by the Subcommittee.

As work begins on the fiscal year 2012 Labor-HHS appropriations bill, the NHC urges the Subcommittee to take a "global" view of the healthcare system as it identifies funding priorities for the coming year. The NHC and its membership, particularly those groups representing the patient community, stress that no one aspect of the healthcare system—research, public health, healthcare delivery—can be considered as a separate, stand-alone component. For a true benefit and service to the American people, especially those living with chronic conditions, the healthcare system must function through the effective and productive interaction of its many parts.

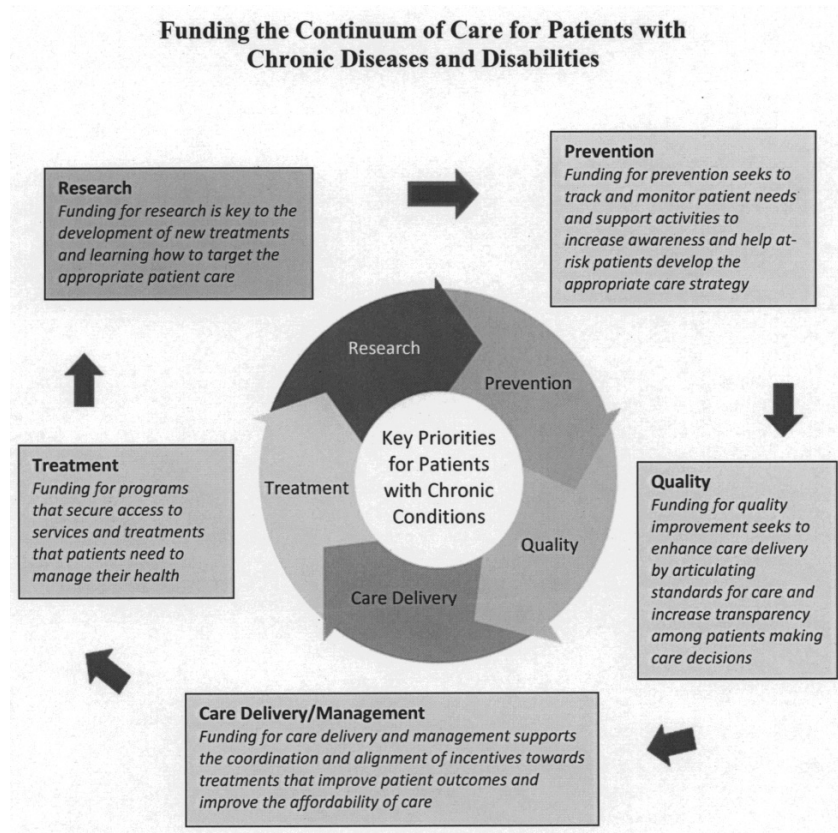
NHC's members have specific interests that span the entire healthcare system. However, a recent survey of our members demonstrated that they share a common concern for the entire continuum of the healthcare system.

One aspect of the healthcare system that is of concern to the NHC is patient access to care. With healthcare costs rising and a growing number of uninsured Americans, far too many people living with chronic conditions are not able to access the care needed to maintain their health and productivity. This is a concern not just for each individual patient but the health system as a whole, which will face greater costs due to declining public health. While the NHC views the entire healthcare system as important, we recognize that the most vitally important piece is for patients to be able to obtain high quality, patient-focused care. Without this, the various components are unable to serve their intended function and the system as a whole falters.

Another large concern of the patient community is the lack of effective cures and treatments. Too many people who are facing serious and life-threatening conditions are doing so without the hope of a cure or even a treatment for their symptoms. Funding for biomedical research at the National Institutes of Health (NIH) offers this hope. But the drug development pipeline does not end with the NIH. Many therapeutics are taking longer to reach patients due to a backlog at the Food and Drug Administration (FDA). While the scope of FDA regulation has grown to the point that it is now regulating one-third of the U.S. economy, the agency's funding has remained relatively consistent. This fact is troubling to the patient advocacy organizations that represent people who lack effective cures and treatments. Both NIH and FDA must be adequately funded to increase the likelihood that these patients will live longer, healthier, and more productive lives.

The NHC appreciates the opportunity to submit this written testimony to the Subcommittee. We understand that you face many hard decisions and again urge that you focus on the healthcare system as continuum that patients must be able

to access in order to best serve the needs of Americans living with chronic conditions.



PREPARED STATEMENT OF THE NATIONAL HEALTHY MOTHERS HEALTHY BABIES COALITION

Highlighting the urgent need to address the startling infant mortality rates in the United States by strengthening programs at HRSA's Maternal and Child Health Bureau.

Mr. Chairman and Members of the Subcommittee, thank you for giving the National Healthy Mothers, Healthy Babies Coalition (HMHB) the opportunity to provide testimony as the Subcommittee begins to consider funding priorities for fiscal year 2012. My name is Judy Meehan and I am the Chief Executive Officer of HMHB, an organization founded in 1981, prompted by the U.S. Surgeon General's conference on infant mortality. Since its founding, HMHB has become a recognized leader and resource in maternal and child health, reaching an estimated 10 million healthcare professionals, parents, and policymakers annually through its membership of over 100 local, State and national organizations.

Mr. Chairman, I would like to limit my testimony today to discuss an exciting program of HMHB, referred to as the text4baby program. This program is focused on improving the health outcomes of mothers and babies and demonstrating the potential of mobile health technology to reach underserved populations with critical health information. Of the 33 countries that the International Monetary Fund describes as "advanced economies" the United States now has the highest infant mortality rate according to data from the World Bank. In 1980, we were 13th and in 2000 we were 2d. In the United States approximately 28,000 babies die before their first birthday, despite a volume of science around behaviors that improve a baby's

chances for a healthy birth and opportunity to thrive. The text4baby program was launched to help address this problem.

Though the text4baby program has been financed by generous funding from Founding Sponsor Johnson & Johnson, with technical and in-kind support from Voxiva and CTIA—The Wireless Foundation, we are hopeful that with your leadership, the Health Resources and Services Maternal and Child Health Bureau can commit to helping us expand this program in two States where there is demonstrated and significant need. The Maternal and Child Health Block Grant program provides a flexible source of funding that allows States to target their most urgent maternal and child health needs. The program supports a broad range of activities including reducing infant mortality. HMHB recommends that funding from within the base of the block grant's Special Projects of Regional and National Significance (SPRANS) be provided to text4baby so that enrollment in this program could be expanded to targeted and special populations in Louisiana and Mississippi, the two States that have the worst infant mortality outcomes. Mr. Chairman, HMHB also recommends fiscal year 2012 funding for the Maternal and Child Health Block Grant program of \$695 million, an increase of \$33 million or 5 percent above the level provided in the fiscal year 2011 continuing resolution.

Text4baby Program

Text4baby, a free mobile information service designed to promote maternal and child health, was developed to deliver evidence-based health information to the women who need it most: the 1.5 million women on Medicaid who give birth each year. While many of these women may lack access to the Internet and other sources of health information, the vast majority of them do have a cell phone, and a reported 80 percent of Medicaid beneficiaries are active texters. Text4baby provides pregnant women and new moms with information they need to take care of their health and give their babies the best possible start in life. Women who sign up for the service receive free SMS text messages each week, timed to their due date or baby's date of birth. Since its launch in February 2010, text4baby has enrolled over 157,000 users and delivered over 12 million evidence-based tips to help them women keep themselves and their babies healthy. That's a great start but it's not enough. Thanks to the grassroots efforts of more than 500 text4baby partners across the country, we are on track to achieve our goal of bringing the service to 1 million moms by 2012 and delivering over 100 million timely and relevant health messages.

The text4baby program was developed in collaboration with the Centers for Disease Control and Prevention (CDC), Health Resources and Services Administration (HRSA), American Academy of Pediatrics (AAP), and other experts. Text4baby messages cover topics like immunization, nutrition, smoking cessation, safe sleep, and the importance of early prenatal care. The content also connects women to services such as health insurance, childcare, and toll-free "quitlines" for assistance in becoming smoke- and drug-free. Text4baby has also delivered urgent infant product alerts at the request of the Food and Drug Administration and outbreak and immunization alerts at the request of CDC. Just last month, text4baby moms saw: "Breaking news! The American Academy of Pediatrics announced new car seat guidelines. Kids should now ride in rear facing-car safety seats until age 2."

Evaluation of the Program

Mr. Chairman, we know that the program is effective. Over 96 percent of those enrolled in the program say they would refer a friend to the service. Also, preliminary data analysis indicates that text4baby is reaching the target audience: for example, analysis of enrollment data in Virginia in October, 2010 showed that text4baby utilization is highest in zip codes with lower income levels and higher incidence rates of low birth weight babies. However, we also want to understand if and how text4baby is improving knowledge and changing behavior. There are currently six formal evaluations underway to examine text4baby's impact. The largest study, funded by the Department of Health and Human Services (HHS) and conducted by Mathematica Policy Research, is a mixed mode study and includes a mobile survey of text4baby users, focus groups, a community survey, electronic health record review, and interviews with key partners. This study will assess utilization of recommended care during prenatal and postpartum periods (considering things such as prenatal visits, postpartum visit, well-child visits, dental visits, and immunization); adherence to recommended health practices (such as breastfeeding and infant sleep position); and adoption of healthy behaviors (such as smoking cessation, healthy eating and exercise).

Even before the formal study results are in, we know that delivering over 12 million important evidence-based health tips to over 160,000 individuals (and, by the

end of next year, 100 million messages to 1 million moms) is an important national service.

Expanding the Program

Glaring disparities in infant mortality exist within certain populations in the United States suggesting the need for a targeted expansion of the program. For example, babies born to African American mothers are most at risk with a rate of 13.5 deaths per 1,000 births. The States with the highest rates of infant mortality are Louisiana (10 babies per 1,000 died before their first birthday) and Mississippi (10.5 babies per 1,000 died before their first birthday). In order to demonstrate the full impact of text4baby, HMHB proposes a targeted outreach and support initiative in those two States. Specifically, HMHB proposes to leverage its great array of activities at the national, regional, State, and local level to meet the ultimate goal of seeing that every woman in Louisiana and Mississippi who is pregnant or a mother of a child less than 1 year enrolls in the service and receives the valuable health information she needs. This targeted outreach will include the development of state-wide implementation teams, technical assistance in the way of event planning and media relations, fulfillment of requests for information, speakers and promotional materials, and support for local data and assessment activities. It will also include targeted outreach for African-American and Hispanic communities. HMHB's zip-code based analysis will allow tracking of the impact of targeted outreach activities with enrollment in real time.

Mississippi and Louisiana Statistics

Since its launch in February 2010, text4baby has enlisted 1,276 users in Mississippi and over 2,768 users in Louisiana; however, in 2007, 46,491 babies were born in Mississippi and 66,301 babies were born in Louisiana. So, clearly, there is work to be done to increase enrollment in these States. Unfortunately, these two States are among the bottom in the Nation in terms of preterm births, low birth weight, and rates of death among children before their first birthday. They are also among the top in terms of smoking and obesity rates (see table below). These are two States in desperate need of a new way to receive information to help them care for their health and give their babies the best possible start in life.

[In percent]

	Mississippi	Louisiana	National
Preterm	18.3	16.6	12.7
Low birth weight	12.3	11.2	8.2
IMR	10.5	10.0	6.7
Women smokers	21.9	22.1	19.6
Men smokers	27.2	25.1	19.6
Obesity in women	37.1	31.5	24.4

Summary and Conclusion

Mr. Chairman, again we wish to thank the Subcommittee for the opportunity to submit testimony and for your leadership in these difficult times. While HMHB recognizes the demands on our Nation's resources, we believe the continuing decline of our Nation's health and the increase in infant mortality justifies a targeted and specific effort. In conclusion, we specifically urge that funding from within the Maternal and Child Health Bureau's SPRANS program be made available for a targeted effort to increase program enrollment among disproportionately impacted populations in Louisiana and Mississippi, the two States with the worst overall outcomes. We also recommend that \$695 million be provided in fiscal year 2012 for the Maternal and Child Health Block Grant Program, an increase of \$33 million or 5 percent over the fiscal year 2011 continuing resolution.

PREPARED STATEMENT OF THE NATIONAL HISPANIC COUNCIL ON AGING (NHCOA)

Thank you for the opportunity to submit written testimony. The National Hispanic Council on Aging (NHCOA) is the leading organization working to improve the lives of Hispanic older adults, their families, and caregivers—the fastest growing segment of the U.S.'s rapidly expanding aging population. For more than 30 years, NHCOA has been a strong voice dedicated to ensuring our Nation's Hispanic seniors enjoy healthy and happy golden years. Alongside its nearly 40 local affiliates across the country, NHCOA reaches ten million Hispanics each year.

Hispanic older adults experience myriad challenges as they seek to obtain a good quality of life in their later years, including health inequities and economic insecurity. They are disproportionately affected by several health afflictions—among them diabetes, hypertension, obesity, and Alzheimer's disease. Exacerbating these problems is the low rate of access to preventative care. Hispanics are disproportionately employed in low-paying jobs that require low levels of formal education or skills and often depend on Social Security as their sole source of income later in life.

NHCOA writes to you today to urge an increase in the funding for the Corporation for National and Community Service's Senior Corps and the Administration on Aging's Older Americans Act Programs. Senior Corps' three programs, the Retired Senior Volunteer Program (RSVP), the Foster Grandparent Program, and the Senior Companion Program, keep the elderly active and allow the community to benefit from their years of wisdom and experience. RSVP connects seniors to volunteer opportunities available in their communities. Foster Grandparents tutor and mentor at-risk children. The Senior Companion Program provides support to volunteers ages 55+ who provide care and friendship to frail elderly. Increasing funding to Senior Corps would provide valuable services to communities while saving Federal funds. According to Pamela Carre of Senior Volunteer Services in Broward County, Florida, during fiscal year 2009, the volunteer work provided by Senior Volunteer Services valued \$6.3 million. All of this work came from Senior Corps volunteers. The Older Americans Act provides a wide variety of nutrition, caretaking, and training programs to thousands of service providers across the country.

The Older Americans Act's National Family Caregiver Support Program and Senior Corps' Senior Companion Program are particularly effective and beneficial for Hispanic older adults. Additional funding to these programs will help meet the needs of Hispanic older adults in a culturally sensitive and effective manner while also easing the financial burden on Medicare and Medicaid.

The Senior Companion program reduces the isolation that can easily trap an elderly person. The Program trains volunteers ages 55+ to assist vulnerable elderly people. In addition to training and placement, the Program also provides a stipend of \$2.65 an hour, reimbursed travel expenses, and accident and liability insurance. Senior Companions assist the elderly, whether by accompanying them on visits to the doctor or running their errands. Administrators of the Senior Companion Program, like Ms. Carre, highlight the importance of the flexible and individualized service these companions provide to other older adults. The main service that all Senior Companions provide is friendship.

The Senior Companion Program benefits the elderly and the economy. Senior Companions provide assistance that allows elderly people to remain independent and out of institutionalized care. Keeping the elderly out of nursing homes and assisted living facilities reduces the cost of healthcare and keeps people from using Medicaid funds. According to Ms. Carre, it costs \$4,800 to support one Senior Companion annually, while one year in a nursing home costs over \$70,000. Additionally, Senior Companions can act as home health aides, providing assistance in the basic activities of daily living. Senior Companions are able to cook for elders, remind them to take their medication, perform housekeeping, and keep family aware of their loved one's needs and condition. This service, also offered by Medicaid and Medicare, can be fulfilled in a cost-effective manner through the Senior Companion Program. In a conversation about the value of senior volunteer programs, Becky Snider, of Pacific Retirement Services in Medford, Oregon, explained that State and local governments recognize the great value these programs provide.

The Senior Companion program has the potential to effectively serve Hispanic older adults in a way that other programs cannot. Many in this group view formal service providers as impersonal and lacking in cultural sensitivity. A dearth of services able to adequately provide assistance to Hispanic older adults further exacerbates this problem. The Senior Companion program can effectively serve Hispanic older adults by offering them friendly and linguistically and culturally sensitive services in their own homes. Senior Companions can help Hispanic older adults manage their health while also providing attention and friendship in a way that home health aides and doctors do not. Ms. Leticia Martinez, the administrator of Senior Companion Volunteer Service of Los Angeles, states that she has heard from many older adults that Senior Companions are often the only people they see on a regular basis and that, "they wouldn't be around without their Senior Companion." Instead of receiving treatment from a home health aide, Senior Companions provide a daily visit from a good friend.

Like a good friend, Senior Companions advocate for, and protect, the older adults with whom they interact. Ms. Martinez stressed that many Senior Companions helped their clients identify and avoid financial abuse. The Senior Companion Program saves money for our seniors.

Although the Senior Companion program can improve the health of seniors and our economy, it is underfunded. The Edward M. Kennedy Serve America Act authorized \$55 million to be appropriated in fiscal year 2010, however, only \$46.9 million was appropriated that year. In fact, the Senior Companion program has not received a substantial increase in funding in at least 10 years. The Senior Companion program deserves an appropriation of at least \$55 million in order to carry out its important duties.

Similar to the Senior Companion Program, the Administration on Aging's National Family Caregiver Support Program (NFCSP) plays a vital role in protecting older adults. The NFCSP provides grants to States to create programs to assist people who care for elderly relatives. These programs support family members in providing the best care possible. The Administration on Aging grants funds for five broad categories: (1) providing information to caregivers about effective caretaking methods and available services; (2) assistance in accessing services; (3) creation of caregiver support groups and training sessions; (4) funds for home health aides to give respite to family caregivers; and (5) on a limited basis, supplemental services.

The NFCSP reduces the financial strain on Medicare and Medicaid. By focusing on maintenance of health and prevention of serious problems, the NFCSP can keep Hispanic older adults out of nursing homes and off Medicaid. Additionally, the ability of NFCSP to provide funding for home health aides and training and respite for family caregivers makes it less likely for older adults to require a Medicare-financed home health aide.

The NFCSP is perfectly suited to help Hispanic older adults, their families, and caregivers. There are valuable, effective programs available to help older adults afford healthcare and nursing home treatment, but many Hispanics feel that traditional healthcare and nursing home programs are too impersonal. The NFCSP addresses this problem by providing respite care and training for effective caregiving and by improving access to caregiving services. Delivering effective, personalized care for older adults in their homes can help manage health issues in a comfortable setting. Furthermore, home health aide services can provide enough respite care for a family caregiver to take on a part-time job, reducing the likelihood that the family will have to turn to Medicaid or other forms of public assistance.

The NFCSP provides support to people who are unexpectedly drawn into helping an older family member. While cleaning and errands may be the first help given to an elderly loved one, these tasks can quickly multiply. The NFCSP teaches family members how to effectively care for their elderly relatives and cope with the stress of such care. Regarding the value of caregiver training and support groups, Mr. Jose Perez, Executive Director of Senior Community Outreach Services in Alamo, Texas says, "I have seen people break down into tears because the stress of caring for their father and how close it brought them to physically abusing their loved one. Training and support groups help them ease this burden."

President Obama's fiscal year 2012 budget request recognizes the importance of the NFCSP and requests a substantial funding increase. In the last several years, the program has received between \$153 million and \$155 million. For fiscal year 2012, President Obama has requested over \$192 million for the NFCSP. This increased funding will help to reduce healthcare costs for seniors while also allowing them to maintain their independence and receive effective treatment from those who know them best. Hispanic older adults will benefit from increased NFCSP funding due to the program's ability to deliver culturally sensitive care to a group that traditional healthcare providers have thus far struggled to adequately serve.

Mr. Perez describes the effectiveness of these two programs with a simple phrase: "Everybody wins." Senior Companions win the satisfaction of helping their fellow citizens and the pride of earning wages for productive work. The elderly win by receiving the care and attention that they deserve. Families win when they learn how to care for their loved ones. The government wins because these programs keep the elderly healthy, independent, and off Medicaid.

NHCOA urges you to appropriate at least \$55 million for the Corporation for National and Community Service's Senior Companion Program. Additionally, we request that you follow President Obama's recommendation and appropriate at least \$192 million for the Administration on Aging's National Family Caregiver Support Program. These two programs will not only effectively serve Hispanic older adults in a way other programs do not, but they will also ease the financial strain on Medicare and Medicaid. Thank you for your consideration, and please feel free to contact NHCOA with any questions or concerns.

PREPARED STATEMENT OF THE NATIONAL KIDNEY FOUNDATION

In 2008, the number of Americans with End Stage Renal Disease (ESRD), which requires dialysis or a kidney transplant to survive, reached 535,000. In that year alone, 110,000 progressed to ESRD. Medicare covers dialysis or transplantation regardless of age or other disability, the only disease-specific coverage under the program. Despite this social and economic impact, no national public health program focusing on early detection and treatment existed until fiscal year 2006, when Congress provided \$1.8 million for the first of 5 years of support to initiate a Chronic Kidney Disease Program at the Centers for Disease Control and Prevention (CDC). Congressional concern regarding kidney disease education and awareness also is found in Sec. 152 of the Medicare Improvements for Patients and Providers Act of 2008 (MIPPA, Public Law 110–275), in which it directed the Secretary to establish pilot projects to increase screening for Chronic Kidney Disease (CKD) and enhance surveillance systems to better assess the prevalence and incidence of CKD. Treatments exist to potentially slow progression of kidney disease and prevent its complications, but only if individuals are diagnosed before the latter stages of CKD.

The CDC program is designed to identify members of populations at high risk for CKD, develop community-based approaches for improving detection and control, and educate health professionals about best practices for early detection and treatment. The National Kidney Foundation respectfully urges the Committee to maintain line-item funding in the amount of \$2.1 million for the Chronic Kidney Disease Program in the CDC's Division of Diabetes Translation. We are encouraged by the fiscal year 2011 Operating Plan for CDC, which recommends only a \$39,000 reduction from the fiscal year 2010 appropriation for the CKD program. Continued support will benefit kidney patients and Americans who are at risk for kidney disease, advance the objectives of Healthy People 2020 and the National Strategy for Quality Improvement in Health Care, and fulfill the mandate created by Sec. 152 of MIPPA.

The prevalence of CKD in the United States, when last measured, was higher than a decade earlier. This is partly explained by the increasing prevalence of the related diseases of diabetes and hypertension. It is estimated that CKD affects 26 million adult Americans¹ and that the number of individuals in this country with CKD who will have progressed to kidney failure, requiring chronic dialysis treatments or a kidney transplant to survive, will grow to 712,290 by 2015². Furthermore, a task force of the American Heart Association noted that decreased kidney function has consistently been found to be an independent risk factor for cardiovascular disease (CVD) outcomes and all-cause mortality and that the increased risk is present with even mild reduction in kidney function.³ Therefore addressing CKD is a way to achieve one of the priorities in the National Strategy for Quality Improvement in Health Care: Promoting the Most Effective Prevention and Treatment of the Leading Causes of Mortality, Starting with Cardiovascular Disease.

Despite the extent of the problem, CKD is an under-recognized and under-treated public health challenge in the United States. Accordingly, Healthy People 2020 Objective CKD–2 is to “increase the proportion of persons with chronic kidney disease (CKD) who know they have impaired renal function.” One reason CKD is neglected is that it is often asymptomatic, especially in the early stages, and, therefore, laboratory testing is required to detect it. Increasing the proportion of persons with CKD who know they are affected requires expanded public and professional education programs and screening initiatives targeted at populations who are at high risk for CKD. Thanks to the interest that this Committee has expressed in CKD in the past, through directed appropriations, the National Center for Chronic Disease Prevention and Health Promotion at CDC has instituted a series of projects that could assist in attaining the Healthy People 2020 objective. However, this forward momentum will be stifled and CDC's investment in CKD to date jeopardized if line-item funding is not continued.

As noted in CDC's Preventing Chronic Disease: April 2006, Chronic Kidney Disease meets the criteria to be considered a public health issue: (1) the condition places a large burden on society; (2) the burden is distributed unfairly among the overall population; (3) evidence exists that preventive strategies that target economic, political, and environmental factors could reduce the burden; and (4) evi-

¹Josef Coresh, et al. “Prevalence of Chronic Kidney Disease in the United States,” JAMA, November 7, 2007.

²D.T. Gilbertson, et al., *Projecting the Number of Patients with End-Stage Renal Disease in the United States to the Year 2015*. J Am Soc Nephrol 16: 3736–3741, 2005.

³Mark J. Sarnak, et al. Kidney Disease as a Risk Factor for the Development of Cardiovascular Disease: A Statement from the American Heart Association Councils on Kidney in Cardiovascular Disease, High Blood Pressure Research, Clinical Cardiology, and Epidemiology and Prevention. Circulation 2003; 108: 2154–69.

dence shows such preventive strategies are not yet in place. Furthermore, CDC convened an expert panel in March 2007 to outline recommendations for a comprehensive public health strategy to prevent the development, progression, and complications of CKD in the United States.

The CDC Chronic Kidney Disease program consists of three projects to promote kidney health by identifying and controlling risk factors, raising awareness, and promoting early diagnosis and improved outcomes and quality of life for those living with CKD. These projects include the following:

- Establishing a surveillance system for Chronic Kidney Disease in the United States.
- Demonstrating effective approaches for identifying individuals at high risk for chronic kidney disease through State-based screening (CKD Health Evaluation and Risk Information Sharing, or CHERISH).
- Conducting an economic analysis by the Research Triangle Institute, under contract with the CDC, on the economic burden of CKD and the cost-effectiveness of CKD interventions.

Pursuant to CHERISH, individuals at high risk for CKD have been screened in eight locations in four States. The goals of the demonstration project have been:

- To educate providers and the public that simple tests can be used to identify CKD in the target population and to assess risk factors for intervention (obesity, hypertension, cardiovascular disease, lipid disorders, diabetes, and glycemic control).
- Evaluate whether providers change practice patterns after being consulted by a person who went through the detection program.

The demonstration project should be replicated at eight sites in four additional States in order to confirm initial findings. If we fail to do so, we could be forfeiting the valuable insight that has been gained thus far.

We believe it is possible to distinguish between the CKD program and other categorical chronic disease initiatives at CDC, because the CKD program does not provide funds to State health departments. Instead, CDC has been making available seed money for feasibility studies in the areas of epidemiological research and health services investigation. Because the CKD program does not provide funds to State health departments, we maintain it should be exempted from the changes in the structure and budget of the National Center for Chronic Disease Prevention and Health Promotion, at least until surveillance planning, and studies of detection feasibility and economic impact are completed.

Thank you for your consideration of our testimony.

PREPARED STATEMENT OF THE NATIONAL LEAGUE FOR NURSING

The National League for Nursing (NLN) is the premiere organization dedicated to promoting excellence in nursing education to build a strong and diverse nursing workforce to advance the Nation's health. With leaders in nursing education and nurse faculty across all types of nursing programs in the United States—doctorate, master's, baccalaureate, associate degree, diploma, and licensed practical—the NLN has more than 1,200 nursing school and healthcare agency members, 34,000 individual members, and 24 regional constituent leagues.

The NLN urges the subcommittee to fund the following Health Resources and Services Administration (HRSA) nursing programs:

- The Nursing Workforce Development Programs, as authorized under Title VIII of the Public Health Service Act, at \$313.075 million in fiscal year 2012; and
- The Nurse Managed Health Clinics, as authorized under Title III of the Public Health Service Act, at \$20 million in fiscal year 2012.

Nursing Education is a Jobs Program

According to the U.S. Bureau of Labor Statistics (BLS), the registered nurse (RN) workforce will grow by 22 percent from 2008 to 2018, resulting in 581,500 new jobs. This growth will be much faster than the average for all occupations. The April 1, 2011 BLS Employment Situation Summary—March 2011 likewise reinforces the strength of the nursing workforce to the Nation's job growth. While the Nation's overall unemployment rate was little changed at 8.8 percent for March 2011, the employment in healthcare increased in March with the addition of 37,000 jobs (i.e., a 36.6 percent rise from February 2011) at ambulatory healthcare services, hospitals, and nursing and residential care facilities.

Nursing is the predominant occupation in the healthcare industry, with more than 3.78 million active, licensed RNs in the United States in 2009. BLS notes that healthcare is a critically important industrial complex in the Nation. Growing stead-

ily even during the depths of the recession, healthcare is virtually the only sector that added jobs to the economy on a net basis since 2001. Over the last 12 months, healthcare added 283,000 jobs, or an average of 24,000 jobs per month.

The Nursing Workforce Development Programs provide training for entry-level and advanced degree nurses to improve the access to, and quality of, healthcare in underserved areas. These Title VIII nursing education programs are fundamental to the infrastructure delivering quality, cost-effective healthcare. The NLN applauds the subcommittee's bipartisan efforts to recognize that a strong nursing workforce is essential to a health policy that provides high-value care for every dollar invested in capacity building for a 21st century nurse workforce.

Yet, the current \$243.872 million in fiscal year 2010 for the Title VIII programs falls short of the healthcare inequities facing our Nation. Absent consistent support, recent boosts to Title VIII will not fulfill the expectation of paying down on asset investments to generate quality health outcomes; nor will episodic increases in funding fill the gap generated by a 13-year nurse shortage felt throughout the entire U.S. health system.

The Nurse Pipeline and Education Capacity

Although the recession resulted in some stability in the short-term for the nurse workforce, policy makers must not lose sight of the long-term growing demand for nurses in their own districts and States. For the complete perspective, the NLN's findings from the Annual Survey of Schools of Nursing—Academic Year 2009–2010 cast a wide net on all types of nursing programs, from doctoral through diploma, to determine rates of application, enrollment, and graduation. The survey creates a true picture of nursing education. Key findings include:

- Expansion of nursing education programs impeded by shortage of faculty and clinical placements. The overall systemic capacity of prelicensure nursing education continues to fall well short of demand. Fully 42 percent of all qualified applications to basic RN programs were met with rejection in 2010. Associate degree in nursing (ADN) programs rejected 46 percent of qualified applications, compared with 37 percent of baccalaureate of science in nursing (BSN) programs. Notably, the Nation's practical nursing (PN) programs turned away 40 percent of qualified applications.
- Yield rates continued to grow. Yield rates—a classic indicator of the competitiveness of college admissions—remain extraordinarily high among both pre- and post-licensure nursing programs. A stunning 94 percent of all applicants accepted into ADN programs, and 93 percent of those accepted in PN programs, went on to enroll in 2010. Yield rates among the other program types were nearly as high, averaging 89 percent for RN-to-BSN programs; 86 percent for RN diploma programs, master's in nursing (MSN) programs, and doctoral programs; and 84 percent for BSN programs.

Nurse Shortage Affected by Faculty Shortage

A strong correlation exists between the shortage of nurse faculty and the inability of nursing programs to keep pace with the demand for new RNs. Increasing the productivity of education programs is a high priority in most States, but faculty recruitment is a glaring problem that likely will grow more severe. Without faculty to educate our future nurses, the shortage cannot be resolved.

The NLN's findings from the 2009 Faculty Census show that:

- Shortages of faculty and clinical placements impeded expansion. A shortage of faculty continues to be cited most frequently as the main obstacle to expansion by RN-to-BSN and doctoral programs—indicated by 47 and 53 percent, respectively. By contrast, prelicensure programs are more likely to point to a lack of available clinical placement settings as the primary obstacle to expanding admissions.
- Inequities in faculty salaries added to shortage difficulties. Despite a national shortage of nurse educators, in 2009 the salaries of nurse educators remained notably below those earned by similarly ranked faculty across higher education. At the professor rank nurse educators suffer the largest deficit with salaries averaging 45 percent lower than those of their non-nurse colleagues. Associate and assistant nursing professors were also at a disadvantage, earning 19 and 15 percent less than similarly ranked faculty in other fields, respectively.

Title VIII Federal Funding Reality

Today's undersized supply of appropriately prepared nurses and nurse faculty does not bode well for our Nation. The Title VIII Nursing Workforce Development Programs are a comprehensive system of capacity-building strategies that provide students and schools of nursing with grants to strengthen education programs, including faculty recruitment and retention efforts, facility and equipment acquisition,

clinical lab enhancements, and loans, scholarships, and services that enable students to overcome obstacles to completing their nursing education programs. HRSA's Title VIII data below provide perspective on a few of the current Federal investments.

Nurse Education, Practice, Quality, and Retention Grants (NEPQR).—NEPQR funds projects addressing the critical nursing shortage via initiatives designed to expand the nursing pipeline, promote career mobility, provide continuing education, and support retention. In fiscal year 2010, NEPQR funded 108 infrastructure grants, including the launching of 22 nurse-managed health centers, four nurse internships, and five new accelerated baccalaureate programs. Also in fiscal year 2010, the program expanded with the Nursing Assistant (NA) and Home Health Aide (HHA) program awarding grants to 10 colleges or community-based training programs.

Comprehensive Geriatric Education Program (CGEP).—CGEP funds training, curriculum development, faculty development, and continuing education for nursing personnel who care for older citizens. In academic year 2009–2010, 27 CGEP grantees provided education and training to 3,030 RNs/RN students; 260 advanced practice registered nurses (APRNs); 221 faculty; 110 HHSs; 483 LPNs/LPN students; 730 NAs; 810 allied health professionals; and 929 laypersons, guardians, activity directors.

Advanced Nursing Education (ANE) Program.—ANE supports infrastructure grants to schools of nursing for advanced practice programs preparing nurse-midwives, nurse anesthetists, clinical nurse specialists, nurse administrators, nurse educators, public health nurses, or other advanced level nurses. In addition, the Advanced Nursing Education Expansion (ANEE) program provides grants to schools of nursing to accelerate the production of primary care advanced practice nurses. In fiscal year 2009, 151 schools of nursing received grants through the ANE Program and enrolled 7,518 advanced nursing education students. In fiscal year 2010, 26 schools of nursing received grants under ANEE to support the production of over 600 primary care APRNs.

Nurse Managed Health Clinics (NMHC)

Most leading authorities recognize that there will be a shortage of primary care providers over the next decade. With the recent growth of NMHCs, APRNs have demonstrated their flexibility as they practice independently or collaborate with physicians in both primary care and specialty areas. This shift suggests that professionals' practice can be directed to changing workforce and population needs as the increased use of APRNs holds the potential for improving access, reducing costs for high-value care, and changing patterns of care.

NMHCs deliver comprehensive primary healthcare services, disease prevention, and health promotion in medically underserved areas for vulnerable populations. Approximately 58 percent of NMHC patients either are uninsured, Medicaid recipients, or self-pay. The complexity of care for these patients presents significant financial barriers, heavily affecting the sustainability of these clinics.

In fiscal year 2010, HRSA awarded \$15,268,000 for 10 3-year infrastructure grants to community-based NMHCs. While providing access points in areas where primary care providers are in short supply, the expansion of the NMHCs also increased the number of structured clinical teaching sites available to train nurses and other primary care providers. These clinics funded by HRSA in fiscal year 2010 expect to train 900 primary care nurse practitioners during their 3-year grants. Appropriating \$20 million in fiscal year 2012 to NMHCs would increase access to primary care for thousands of uninsured people in rural and underserved urban communities. The funding of additional NMHCs likewise will enable schools of nursing to increase innovative clinical teaching site opportunities for nursing students, which will directly expand the capacity of nursing school enrollments.

The NLN can state with authority that the deepening health inequities, inflated costs, and poor quality of healthcare outcomes in this country will not be reversed until the concurrent shortages of nurses and qualified nurse educators are addressed. Your support will help ensure that nurses exist in the future who are prepared and qualified to take care of you, your family, and all those who will need our care. Without national efforts of some magnitude to match the healthcare reality facing our Nation today, a calamity in nurse education and in healthcare generally may not be avoided.

The NLN urges the subcommittee to strengthen the Title VIII Nursing Workforce Development Programs by funding them at a level of \$313.075 million in fiscal year 2012. We also recommend that the Nurse Managed Health Clinics, as authorized under Title III of the Public Health Service Act, be funded at \$20 million in fiscal year 2012.

PREPARED STATEMENT OF THE NATIONAL MARFAN FOUNDATION

Mr. Chairman, thank you for the opportunity to submit testimony regarding the fiscal year 2012 budget for the National Heart, Lung and Blood Institute, the National Institute of Arthritis, Musculoskeletal and Skin Diseases, and the Centers for Disease Control and Prevention. The National Marfan Foundation is grateful for the subcommittee's strong support of the NIH and CDC, particularly as it relates to life-threatening genetic disorders such as Marfan syndrome. Thanks in part to your leadership we are at a time of unprecedented hope for our patients.

It is estimated that 200,000 people in the United States are affected by Marfan syndrome or a related condition. Marfan syndrome is a genetic disorder of the connective tissue that can affect many areas of the body, including the heart, eyes, skeleton, lungs and blood vessels. It is progressive condition and can cause deterioration in each of these body systems. The most serious and life-threatening aspect of the syndrome is a weakening of the aorta. The aorta is the largest artery carrying oxygenated blood from the heart. Over time, many Marfan syndrome patients experience a dramatic weakening of the aorta which can cause the vessel to dissect and tear.

Early surgical intervention can prevent a dissection and strengthen the aorta and the aortic valves. If preventive surgery is performed before a dissection occurs, the success rate of the procedure is over 95 percent. If surgery is initiated after a dissection has occurred, the success rate drops below 50 percent. Aortic dissection is a leading killer in the United States, and 20 percent of the people it affects have a genetic predisposition, like Marfan syndrome, to developing the complication.

Fortunately, new research offers hope that a commonly prescribed blood pressure medication might be effective in preventing this frequent and devastating event.

FISCAL YEAR 2012 APPROPRIATIONS RECOMMENDATIONS

National Institutes of Health

Mr. Chairman, hope for a better quality of life for patients with Marfan syndrome and related connective tissue disorders lies in NIH-sponsored biomedical research. With that in mind, NMF joins with other voluntary patient and medical organizations in recommending an appropriation of \$35 billion for the National Institutes of Health in fiscal year 2012. This level of funding will ensure continued expansion of research on rare diseases like Marfan syndrome and build upon the significant investment provided to the NIH in the American Recovery and Reinvestment Act.

*National Heart, Lung, and Blood Institute**Pediatric Heart Network Clinical Trial*

NMF applauds the National Heart, Lung and Blood Institute for its leadership in advancing a landmark clinical trial on Marfan syndrome. Under the direction of Dr. Lynn Mahoney and Dr. Gail Pearson, the institute's Pediatric Heart Network (PHN) has spearheaded a multicenter study focused on the potential benefits of a commonly prescribed blood pressure medication (losartan) on aortic growth in Marfan syndrome patients.

Dr. Hal Dietz, the Victor A. McKusick Professor of Genetics in the McKusick-Nathans Institute of Genetic Medicine at the Johns Hopkins University School of Medicine, and the director of the William S. Smilow Center for Marfan Syndrome Research, is the driving force behind this groundbreaking research. Dr. Dietz uncovered the role that the growth factor TGF-beta plays in aortic enlargement, and demonstrated the benefits of losartan in halting aortic growth in mice. He is the reason we have reached this time of such promise and NMF is proud to have supported Dr. Dietz's cutting-edge research for many years.

After 4 years of recruitment and patient screening, the PHN trial reached its enrollment target of 604 subjects on February 2, 2011. Marfan syndrome patients (age 6 months to 25 years) are enrolled in the study. Patients are randomized onto either losartan or atenolol (a beta blocker that is the current standard of care for Marfan patients with an enlarged aortic root).

We anxiously await the results of this first-ever clinical trial for our patient population. It is our hope that losartan will emerge as the new standard-of-care and greatly reduce the need for surgery in at-risk patients.

Mr. Chairman, NMF is proud to actively support the losartan clinical trial in partnership with the Pediatric Heart Network. Throughout the life of the trial we have provided support for patient travel costs, coverage of select echocardiogram examinations, and funding for ancillary studies. These ancillary studies will explore the impact that losartan has on other manifestations of Marfan syndrome.

Evaluation of Surgical Options for Marfan Syndrome Patients

Mr. Chairman, we are grateful for the subcommittee's previous recommendations encouraging NHLBI to support research on surgical options for Marfan syndrome patients.

For the past several years, the NMF has supported an innovative study looking at outcomes in Marfan syndrome patients who undergo valve-sparing surgery compared with valve replacement. Initial findings were published last year in the *Journal of Thoracic and Cardiovascular Surgery*. Some short term questions have been answered, most importantly that valve-sparing can be done safely on Marfan patients by an experienced surgeon. The consensus among the investigators however is that long-term durability questions will not be answered until patients are followed for at least 10 years.

Confirming the utility and durability of valve sparing procedures will save our patients a host of potential complications associated with valve replacement surgery. We hope to partner with the NIH on this important work moving forward.

NHLBI "Working Group on Research in Marfan Syndrome and Related Conditions"

In 2007, NHLBI convened a "Working Group on Research in Marfan Syndrome and Related Conditions." Chaired by Dr. Dietz, this panel was comprised of experts in all aspects of basic and clinical science related to the disorder. The panel was charged with identifying key recommendations for advancing the field of research in the coming decade. The recommendations of the Working Group are as follows:

Scientific opportunities to advance this field are conferred by technological advances in gene discovery, the ability to dissect cellular processes at the molecular level and imaging, and the establishment of multi-disciplinary teams. The barriers to progress are addressed through the following recommendations, which are also consistent with Goals and Challenges in the NHLBI Strategic Plan.

- Existing registries should be expanded or new registries developed to define the presentation, natural history, and clinical history of aneurysm syndromes.
- Biological and aortic tissue sample collection should be incorporated into every clinical research program on Marfan syndrome and related disorders and funds should be provided to ensure that this occurs. Such resources, once established, should be widely shared among investigators.
- An Aortic Aneurysm Clinical Trials Network (ACTnet) should be developed to test both surgical and medical therapies in patients with thoracic aortic aneurysms.
- The identification of novel therapeutic targets and biomarkers should be facilitated by the development of genetically defined animal models and the expanded use of genomic, proteomic and functional analyses. There is a specific need to understand cellular pathways that are altered leading to aneurysms and dissections, and to develop robust in vivo reporter assays to monitor TGF β and other cellular signaling cascades.
- The developmental underpinnings of apparently acquired phenotypes should be explored. This effort will be facilitated by the dedicated analysis of both pre-natal and early postnatal tissues in genetically defined animal models and through the expanded availability to researchers of surgical specimens from affected children and young adults.

We look forward to working closely with NHLBI to pursue these important research goals and ask the Subcommittee to support the recommendations of the Working Group.

National Institute of Arthritis and Musculoskeletal and Skin Diseases

NMF is proud of its longstanding partnership with the National Institute of Arthritis and Musculoskeletal and Skin Diseases, which is celebrating its 25th anniversary this year. Dr. Steven Katz has been a strong proponent of basic research on Marfan syndrome during his tenure as NIAMS director and has generously supported several "Conferences on Heritable Disorders of Connective Tissue." Moreover, the Institute has provided invaluable support for Dr. Dietz's mouse model studies. The discoveries of fibrillin-1, TGF β , and their role in muscle regeneration and connective tissue function were made possible in part through collaboration with NIAMS.

As the losartan trial continues to move forward, we hope to expand our partnership with NIAMS to support related studies that fall under the mission and jurisdiction of the Institute. One of the areas of great interest to researchers and patients is the role that losartan may play in strengthening muscle tissue in Marfan patients. We would welcome an opportunity to partner with NIAMS on this and other research.

Centers for Disease Control and Prevention

Mr. Chairman, one of the most important things we can do to prevent untimely deaths from aortic aneurysms is to increase awareness of Marfan syndrome and related connective tissue disorders.

Last year, the American College of Cardiology and the American Heart Association issued landmark practice guidelines for the treatment of thoracic aortic aneurysms and dissections. The NMF is promoting awareness of the new guidelines in collaboration with other organizations through a new Coalition known as TAD; the Thoracic Aortic Disease Coalition. We hope to partner with the CDC in fiscal year 2012 to increase awareness of the guidelines so all patients will be adequately diagnosed and treated. For fiscal year 2012, NMF joins with the CDC Coalition in recommending an appropriation of \$7.7 billion for CDC's core programs.

PREPARED STATEMENT OF THE NATIONAL MINORITY AIDS COUNCIL

The National Minority AIDS Council (NMAC) represents a coalition of over 3,000 community based organizations and AIDS service organizations delivering HIV/AIDS services in communities of color nationwide. Our constituents are on the front lines of the HIV epidemic and are the most affected when funding for HIV/AIDS programs are reduced or eliminated.

Our Nation is facing difficult decisions on how to stabilize the economy and pass a sensible Federal budget. Although we support efficient, cost-effective spending, we cannot support reducing healthcare funding which would adversely affect the health and well being of the most vulnerable: minority communities, with higher rates of poverty where poor health outcomes are often linked to poor access to care. While budget negotiations often focus on cold numbers, it is easy to lose sight of the fact that human lives are at stake.

Cost-effective research and prevention programs that prevent life-threatening diseases such as HIV/AIDS, as well as life-saving access to care and medications for those already infected are critical in preventing avoidable infections, serious illness, and deaths. Although funding has failed to keep up with demand, it is impossible to deny the strides in prevention, research, and treatment of HIV/AIDS that has been supported by previous appropriations.

We now have a National HIV/AIDS Strategy which sets attainable goals in reducing the devastation caused by this epidemic. The Strategy calls for a reduction of new infections by 25 percent in the next 5 years as well as improved access to care for those already infected. As we continue to move forward in trying to reduce new infections and saving precious lives through the Strategy, it is imperative that the existing public health and safety net infrastructure be adequately funded.

Health Care Reform

In addition to the Strategy, implementation of healthcare reform offers a monumental opportunity to make progress in reducing the impact of the domestic HIV epidemic by greatly increasing the number of Americans eligible for healthcare access. As such, we request full funding of the President's fiscal year 2012 budget request for healthcare reform programs aimed at reducing health disparities. Many of the programs under the Patient Protection and Affordable Care Act (ACA) are funded through discretionary budgets. Increased access to medical care through venues such as Community Health Centers are welcomed as they provide care in cost effective settings when compared to the emergency room, which are too often the primary source of medical care for communities of color.

Minority AIDS Initiative (MAI)

MAI programs seek to improve HIV-related health outcomes for racial and ethnic minority communities that are disproportionately affected by HIV/AIDS. Central to these goals is the MAI's focus on efforts to strengthen the organizational capacity of community-based providers, in particular minority providers; improve the quality of HIV services; and expand the pool of HIV service providers. NMAC strongly recommends this Committee fund MAI programs at \$610 million for fiscal year 2012 as minority communities continue to carry a disproportionate burden of the epidemic. NMAC does appreciate the President's fiscal year 2012 budget request of \$430.7 million as a minimum budget for MAI.

HIV/AIDS Bureau of the Health Resources and Services Administration (HRSA)

The number of people living with HIV in the United States has grown to over 1.1 million people. That fact coupled with the skyrocketing costs of medical care creates a dire need for substantial increases in funding for care and treatment. We urge you to increase funding for the Ryan White program by \$350 million in fiscal year

2012. At minimum, we strongly urge you to support the President's proposed fiscal year 2012 increase of \$69.3 million for the Ryan White program over fiscal year 2010.

As a payer of last resort, Ryan White provides critical access to treatment and medications to under-insured and uninsured people. Part A funds are used to provide a continuum of care for people living with HIV disease. To support this critical component, we request an increase of \$74.2 million when compared to fiscal year 2010. Part B funds are provided to States to improve their capacity to provide medical care. It also funds the AIDS Drug Assistance program (ADAP), which currently has a wait list of over 8,100 people with no other means to access medications. Eleven States have implemented waiting lists and many others have implemented cost containment strategies since funding is not keeping up with demand. We request an increase of \$76.8 million in funding to States as compared to fiscal year 2010 and an increase of \$106 million for ADAP.

Centers for Disease Control and Prevention's (CDC) National Center for HIV/AIDS, Viral Hepatitis, STD, and TB Prevention (NCHHSTP)

With over 56,000 new infections annually, a renewed emphasis on prevention and early HIV screening is critical at this juncture. NMAC urges total fiscal year 2012 funding of \$1,983.9 million for the CDC's NCHHSTP. This includes funding of \$1,325.7 million for HIV prevention and surveillance, \$59.8 million for viral hepatitis and \$231 million for tuberculosis prevention. We appreciate that the President proposed a \$1,178.5 million budget for HIV prevention at the CDC, and at a bare minimum we urge the Committee to meet this request.

National Institutes of Health (NIH)—Office of AIDS Research

HIV/AIDS research has made great strides in understanding and improving HIV treatment, viral suppression, and various prevention tools. Continued commitment to a thorough AIDS research portfolio is necessary to build on past innovation. In order to build on this research and continue to see how these interventions affect communities of color, NMAC requests \$3.5 billion to support the Office of AIDS Research. Additionally, NMAC believes that \$35 billion to fund NIH's overall programs and infrastructure.

Investments in prevention, treatment and research for HIV, as well as comorbidities, must keep pace with the epidemic if we are to see real progress in reducing new infections, disease burden, and untimely deaths due to this devastating disease.

PREPARED STATEMENT OF THE NATIONAL MINORITY CONSORTIA

The National Minority Consortia (NMC) submits this statement on the fiscal year 2014 Advance appropriation for the Corporation for Public Broadcasting (CPB). The NMC is a coalition of five national organizations dedicated to bringing the unique voices and perspectives from America's diverse communities into all aspects of public broadcasting and to other media, including content transmitted digitally over the Internet. The role we fulfill in this regard has been crucial to public broadcasting's mission for over 30 years. We are unique as organizations and as a coalition of organizations in the services we provide in access, training and support for important and timely public interest content to our communities and to public broadcasting. We ask the Committee to:

- Direct CPB to increase its efforts for diverse programming with commensurate increases for minority programming and for organizations and stations located within underserved communities;
- Direct CPB to establish a percentage basis for biennial funding of the National Minority Consortia to permit long range financial and strategic planning;
- Direct CPB to establish an annual "report card" on diversity to track efforts to better represent the full breadth of the American people and their experiences through public television, public radio and non-profit media online;
- Direct CPB to publish on the Internet clear and enforced guidelines for all CPB-directed funding, including funds jointly administered by PBS and NPR, and end the closed-door funding processes historically in place, especially as the current practices favor existing relationships and can be seen as biased against minority applicants, in particular.

Report Language.—We ask for report language, which recognizes the contribution of the NMC and directs that the CPB partnership with us be expanded. Specifically:

"The Committee recognizes the importance of the partnership CPB has with the National Minority Public Broadcasting Consortia, which helps develop, acquire, and

distribute public television programming to serve the needs of African American, Asian American, Latino, Native American, Pacific Islander, and many other viewers. As many communities in the Nation welcome increased numbers of citizens of diverse ethnic backgrounds, the local public television stations should strive to meet these viewers' needs. With an increased focus on programming to meet local community needs, the Committee encourages CPB to support and expand this critical partnership."

Fiscal Year 2014 Appropriation.—We support a fiscal year 2014 advance appropriation for CPB of \$495 million, which recognizes the need to develop content that reaches across traditional media boundaries, such as those separating television and radio. However, we feel strongly that should CPB receive this appropriation, CPB should be directed to engage in transparent and fair funding practices that guarantee all applicants equal access to these public resources. In particular, we urge Congress to direct CPB to insert language in all of its funding guidelines that encourages and rewards public media that fully represents and reaches a diverse American public.¹

While public broadcasting continues to uphold strong ethics of responsible journalism and thoughtful examination of American history, life and culture, including the ways we are a part of a global society, it has not kept pace with our rapidly changing public as far as diversity is concerned. Members of minority groups continue to be underrepresented on both the programming and oversight levels within public broadcasting as well as on the content production side. There are fewer than five executives of diverse background at the highest levels in the three leading organizations within public broadcasting. This is unacceptable in America today, where minorities comprise over 35 percent of the population.

Public broadcasting has the potential to be particularly important for our Nation's growing minority and ethnic communities, especially as we transition to a broadband-enabled, 21st century workforce that relies on the skills and talent of all of our citizens. While there is a niche in the commercial broadcast and cable world for quality programming about our communities and our concerns, it is in the public broadcasting sphere where minority communities and producers should have more access and capacity to produce diverse high-quality programming for national audiences. We therefore, urge Congress to insert strong language in this act to ensure that this is the case and that these opportunities are made available to minorities and other underserved communities.

About the National Minority Consortia.—With primary funding from the CPB, the NMC serves as an important component of American public television as well as content delivered over the Internet. By training and mentoring the next generation of minority producers and program managers as well as brokering relationships between content makers and distributors (such as PBS, APT and NETA), we are in a perfect position to ensure the future strength and relevance of public television and radio television programming from and to our communities. However, these efforts are vulnerable because of chronic underfunding and lack of meaningful and ongoing representation within CPB's decisionmaking processes. This instability, coupled with what is essentially a decrease in our funding over time, are the primary reasons that have led to a public media that has become less diverse over the past 5 years.²

This is obviously not the case in the rest of America. With minority populations already estimated at over 35 percent of the U.S. population, it is more important that our public institutions reflect this reality.

Individually, each Consortia organization is engaged in cultivating ongoing relationships with the independent producer community by providing technical assistance and program funding, support and distribution. Often the funding we provide is the initial seed money for a project, thus allowing it to develop. We also provide numerous hours of programming to individual public television and radio stations, programming that is beyond the production reach of most local stations. To have

¹According to the 2008 Public Radio Tech Survey, 90 percent of public radio listeners are white. Of those, 84 percent are college-educated, with 48 percent having graduate degrees. This compares to just 9 percent of Americans who have postgraduate degrees. It is therefore mandatory that we prioritize actually "reaching" a diverse audience of Americans and not simply reflecting diverse and often misleading staffing numbers to measure public media's effectiveness in serving all of the American taxpayers that fund CPB.

²CPB funding for the NMC remained flat for 13 years until fiscal year 2008, at approximately \$1 million per year per consortia. At that time, we received a one-time increase of \$150,000 per organization. In fiscal year 2009, we received another one-time increase of approximately \$500,000 each, but have been told that does not reflect a permanent increase. Over this same 13-year period, CPB's budget nearly doubled.

a real impact, we need funding that recognizes and values the full extent of minority participation in public life.

While the Consortia organizations work on projects specific to their communities, the five organizations also work collaboratively. An example of a joint production in which the NMC provided the initial seed money is “Unnatural Causes: Is Inequality Making Us Sick?”, a multi-part series that uncovers the roots of racial and socio-economic disparities in health and spotlights community initiatives to achieve health equality. Our seed money enabled the project to go forward and to attract additional funding. We are also co-producers of and presenters in this series. Additionally, we jointly funded an online initiative around the Presidential Election in 2008 and continue to explore as a group other topics of national importance.

CPB Funds for the National Minority Consortia.—The NMC receives funds from two portions of the CPB budget: organizational support funds from the Systems Support and programming funds from the Television Programming funds. The organizational support funds we receive are used for operations requirements and also for programming support activities and for outreach to our communities and system-wide within public broadcasting. The programming funds are re-granted to producers, used for purchase of broadcast rights and other related programming activities. Each organization solicits applications from our communities for these funds. A brief description of our organizations follows:

Center for Asian American Media (CAAM).—CAAM’s mission is to present stories that convey the richness and diversity of Asian American experiences to the broadest audience possible. We do this by funding, producing, distributing and exhibiting works in film, television and digital media. Over our 25-year history we have provided funding for more than 200 projects, many of which have gone on to win Academy, Emmy and Sundance awards, examples of which are *Daughter from Danang*; *Of Civil Rights and Wrongs: The Fred Korematsu Story*; and *Maya Lin: A Strong Clear Vision*. CAAM presents the annual San Francisco International Asian American Film Festival and distributes Asian American media to schools, libraries and colleges. CAAM’s newest department, Digital Media is becoming a respected leader in bringing innovative content and audience engagement to public media. CAAM is partnering with Pacific Islanders in Communications on a documentary about YouTube ukulele sensation Jake Shimabukuro.

Latino Public Broadcasting (LPB).—LPB supports the development, production and distribution of public media content that is representative of Latino people, or addresses issues of particular interest to Latino Americans. Since 1998, LPB has awarded over \$6 million to Latino Independent Producers, provided over 120 hours to public television, funded over 200 projects and conducted over 150 professional development workshops. LPB also produces *Voces*, the only Latino anthology series on public television, which showcases the impact of Latino culture on American life through music, sports, education and public service. In addition, LPB had several high profile programs on PBS including the concert special, *In Performance at the White House: Fiesta Latina*, that was re-broadcast on Telemundo and V-me and *Latin Music USA*, a four part series about the history and impact of Latino music on American culture which reached 14.7 million viewers, 16 percent of whom were Hispanic households (well above the PBS average). This past year, LPB launched the Equal Voice Community Engagement Campaign using the documentary film *Raising Hope: The Equal Voice Story*, a film about strategies to overcome poverty. The community engagement campaign helped PBS stations demonstrate how they too can become advocates for their communities. Currently, LPB is working on a 6 hour series titled *The Latino Americans*, about the history of Latinos in the United States.

The National Black Programming Consortium (NBPC).—NBPC develops, produces and funds television and more recently audio and online programming about the black experience for American public media outlets. Since its founding in 1979, NBPC has provided hundreds of broadcast hours documenting African American history, culture and experience to public television and launched major initiatives that have brought important public media content to diverse audiences. In 2010, the National Black Programming Consortium launched an ambitious new project designed to re-engineer public media to better involve and inform diverse users in the digital era: The Public Media Corps (PMC). The PMC is a new national public media service that helps local stations to forge relationships with underserved communities through content production, local events, and digital media training. By recruiting, training and supporting the work of young, tech savvy “fellows” from these communities the PMC provides both stations and community partner organizations with a blueprint for not only connecting with audiences who have traditionally not found public broadcasting relevant to their lives, but also by providing them with access to emerging participatory platforms.

Native American Public Telecommunications (NAPT).—NAPT shares Native stories with the world through support of the creation, promotion and distribution of Native media. Founded in 1977, through various media—public television and radio, and the Internet—NAPT brings awareness of Indian and Alaska Native issues.

In 2010 NAPT presented eight Native American documentaries to PBS stations nationwide and launched a search capable educational micro-site featuring educational guides, post-viewer discussion guides, digital media clips, and interactive time lines. NAPT offered producers numerous workshops related to media maker topics such as preparation for broadcast, marketing your film on a budget, station carriage, online promotional tools, podcasting and more through nationwide media maker training offerings and conference attendance opportunities. In addition NAPT launched the Multimedia Fellowship Program, where two full-time Native American journalists wrote and produced multimedia projects about national Native American issues. Through our location at the University of Nebraska-Lincoln, we offer student employment, internships and fellowships. Reaching the general public and the global market is the ultimate goal for the dissemination of Native-produced media.

Pacific Islanders in Communications (PIC).—Since 1991, PIC has delivered programs and training that bring voice and visibility to Pacific Islander Americans. PIC produced the award winning film *One Voice* which tells the story of the Kamehameha Schools Song Contest. Other PBS broadcasts include *There Once Was an Island*, about the devastating effects of global warming on the Pacific Islands and *Polynesian Power: Islanders in Pro Football*. Currently PIC is developing a multi-part series, *Expedition: Wisdom*, in partnership with the National Geographic Society. PIC offers a wide range of development opportunities for Pacific Island producers through travel grants, seminars and media training. Producer training programs are held in the U.S. territories of Guam and American Samoa, as well as in Hawai'i, on a regular basis.

Thank you for your consideration of our recommendations. We see new opportunities to increase diversity in programming, production, audience, and employment in the new media environment, and we thank Congress for support of our work on behalf of our communities.

PREPARED STATEMENT OF THE NATIONAL MULTIPLE SCLEROSIS SOCIETY

Multiple sclerosis (MS), an unpredictable, often disabling disease of the central nervous system, interrupts the flow of information within the brain, and between the brain and body. Symptoms range from numbness and tingling to blindness and paralysis. The progress, severity, and specific symptoms of MS in any one person cannot yet be predicted, but advances in research and treatment are moving us closer to a world free of MS. Most people with MS are diagnosed between the ages of 20 and 50, with at least two to three times more women than men being diagnosed with the disease. MS affects more than 400,000 people in the United States.

The National MS Society recommends the following funding levels for agencies and programs that are of vital importance to Americans living with MS in fiscal year 2012.

Lifespan Respite Care Program

Respite care services are a critical part of ensuring quality home-based care for people living with MS. Because of the importance of these services, the National MS Society requests the inclusion of \$50 million in the fiscal year 2012 Labor-HHS-Education appropriations bill to fund lifespan respite programs. The Lifespan Respite Care Program, enacted in 2006, provides competitive grants to states to establish or enhance statewide lifespan respite programs, improve coordination, and improve respite access and quality. States provide planned and emergency respite services, train and recruit workers and volunteers, and assist caregivers in gaining access to services. Perhaps the most critical aspect of the program for people living with MS is that Lifespan Respite serves families regardless of special need or age—literally across the lifespan. Much existing respite care has age eligibility requirements and since MS is typically diagnosed between the ages of 20 and 50, Lifespan Respite Programs are often the only open door to needed respite services.

Up to one-quarter of individuals living with MS require long-term care services at some point during the course of the disease. Often, a family member steps into the role of primary caregiver to be closer to the individual with MS and to be involved in care decisions. Approximately 65 million family caregivers in the Nation are responsible for 80 percent of long-term care. The value of uncompensated family care giving services keeps growing and is currently estimated at \$375 billion per year—more than total Medicaid spending and almost as high as Medicare spending.

Family caregiving, while essential, can be draining and stressful, with caregivers often reporting difficulty managing emotional and physical stress, finding time for themselves, and balancing work and family responsibilities. The impact is so great, in fact, that American businesses lose an estimated \$17.1 to \$33.36 billion each year due to lost productivity costs related to caregiving responsibilities. Providing \$50 million for Lifespan Respite in fiscal year 2012 would provide the critical infrastructure to states to improve access to respite services, allowing family caregivers to take a break from the daily routine and stress of providing care, improve overall family health, and help alleviate the monstrous financial impact that caregiver strain currently has on American businesses.

National Institutes of Health

We urge Congress to continue its investment in innovative medical research that can help prevent, treat, and cure diseases such as MS by providing \$35 billion for the National Institutes of Health (NIH) in fiscal year 2012.

The NIH conducts and sponsors a majority of the MS related research carried out in the United States. Approximately \$151 million of fiscal year 2010 and Recovery Act appropriations were directed to MS-related research. An invaluable partner, the NIH has helped make significant progress in understanding MS. NIH scientists were among the first to report the value of MRI in detecting early signs of MS, before symptoms even develop. Advancements in MRI technology allow doctors to monitor the progression of the disease and the impact of treatment.

Research during the past decade has enhanced knowledge about how the immune system works, and major gains have been made in recognizing and defining the role of this system in the development of MS lesions. These NIH discoveries are helping find the cause, alter the immune response, and develop new MS therapies that are now available to modify the disease course, treat exacerbations, and manage symptoms. The NIH also directly supports jobs in all 50 States and 17 of the 30 fastest growing occupations in the United States are related to medical research or healthcare. More than 83 percent of the NIH's funding is awarded through almost 50,000 competitive grants to more than 325,000 researchers at over 3,000 universities, medical schools, and other research institutions in every State. To continue the forward momentum in the ability to aggressively combat, treat, and one day cure diseases like MS, the National MS Society requests Congress provide \$35 billion for the NIH in fiscal year 2012.

Centers for Medicare & Medicaid Services

Medicare

Medicare programs are a lifeline for people living with MS, as approximately one-quarter of people living with MS rely on Medicare for access to essential medical care. These programs ensure that individuals living with MS have access to doctors, diagnostic equipment, durable medical devices, MRIs, and prescription drugs among other lifesaving treatments. Medicare also ensures full access to home healthcare, which is vital for keeping individuals with disabilities, like MS, in their communities and in their homes. Without Medicare, people living with MS may not have access to some forms of medical care and their quality of life may decrease.

The National MS Society is concerned about recent budget proposals that would essentially convert Medicare from an entitlement program to a voucher-type program. While proponents of these proposals believe that they will cut costs of the program, in reality the voucher system would primarily shift costs from the Medicare program to patients and consumers. In fact, the Congressional Budget Office has estimated that by 2030, the typical Medicare beneficiary would be required to pay more than two-thirds of their medical costs. Additionally, according to the Kaiser Family Foundation, a typical 65-year-old retiring in 2022 would be expected to devote nearly half their monthly Social Security checks toward healthcare costs, more than double what they would spend under current Medicare law.

Beginning in 2022, the proposed system would give new beneficiaries money to purchase insurance from the private market, under the assumption that beneficiaries can make better and more cost-effective decisions about healthcare than the government and that this open market will create competition that will help keep costs down. However, the size of Medicare allows the program to impose lower rates on medical services and thus, private plans on average are more expensive. Therefore, the proposed voucher system may reduce costs within the Medicare program but not within the overall healthcare system because it will shift more cost to some of the most vulnerable patients in the healthcare system. In order to continue to provide the adequate and necessary care individuals with MS and other disabilities require, Medicare must maintain its status as an entitlement program.

Medicaid

The National MS Society urges Congress to maintain funding for Medicaid and reject proposals to cap or block grant the program.

Approximately 10 percent of people living with MS rely on Medicaid. The program has a strong track record of providing services that grant individuals with disabilities access to employment, cost-effective health services, home- and community-based services, and long-term care.

Capping or block-granting Medicaid will merely shift costs to states, forcing states to shoulder a seemingly insurmountable financial burden or cut services on which our most vulnerable rely. Capping and block-granting could result in many more individuals becoming uninsured, compounding the current problems of lack of coverage, over flowing emergency rooms, limited access to long term services, and increased healthcare costs in an overburdened system. By capping funds that support home- and community-based care, such proposals would also likely lead to an increased reliance on costlier institutional care that contradicts the principles laid forth in the 1999 U.S. Supreme Court *Olmstead* decision of integrating and keeping people with disabilities in their communities.

While the economic situation demands leadership and thoughtful action, the National MS Society urges Congress to remember people with MS and all disabilities, their complex health needs, and the important strides Medicaid has made for persons living with disabilities, particularly in the area of community-based care and not modify the program to their detriment.

Social Security Administration

The National MS Society urges Congress to provide \$12.522 billion for the Social Security Administration's (SSA) Limitations on Administrative (LAE) Expenses to fund SSA's day-to-day operational responsibilities and make key investments in addressing increasing disability and retirement workloads, in program integrity, and in SSA's Information Technology (IT) infrastructure.

Because of the unpredictable nature and sometimes serious impairment caused by the disease, SSA recognizes MS as a chronic illness or "impairment" that can cause disability severe enough to prevent an individual from working. During such periods, people living with MS are entitled to and rely on Social Security Disability Insurance (SSDI) or Supplemental Security Income (SSI) benefits to survive. People living with MS, along with millions of others with disabilities, depend on SSA to promptly and fairly adjudicate their applications for disability benefits and to handle many other actions critical to their well-being including: timely payment of their monthly benefits; accurate withholding of Medicare Parts B and D premiums; and timely determinations on post-entitlement issues, e.g., overpayments, income issues, prompt recording of earnings.

With an expected increase in disability claims of nearly 29 percent between fiscal year 2008 and fiscal year 2010, SSA faces an unprecedented backlog in unprocessed disability claims. The average processing time is fortunately improving due to recent investments in and appropriations to SSA and as of March 2010, was approximately 437 days or a little more than 14 months. This progress must continue.

Providing at least \$12.522 billion for the SSA is necessary to continue these programs and advancements, which are integral parts of efficiently and effectively getting benefits to individuals with disabilities, including those with MS.

Food and Drug Administration

Because of the tremendous impact the FDA has on the development and availability of drugs and devices for individuals with disabilities, the National MS Society requests that Congress provide a 15 percent increase over the fiscal year 2011 budget.

Advancements in medical technology and medical breakthroughs play a pivotal role in decreasing the societal costs of disease and disability. The FDA is responsible for approving drugs for the market and in this capacity has the ability to keep healthcare costs down. Each dollar invested in the life-science research regulated by the FDA has the potential to save upwards of \$10 in health gains. Breakthroughs in medication and devices can reduce the potential costs of disease and disability in Medicare and Medicaid and can help support the healthier, more productive lives of people living with chronic diseases and disabilities, like MS. The approval of low-cost generic drugs saved the healthcare system \$140 billion last year and nearly \$1 trillion over the past decade. However, recent funding constraints have resulted in a 2 year backlog of generic drug approval applications and could potentially cost the Federal Government and patients billions of dollars in the coming years. The potential for these cost-saving medical breakthroughs and overall healthcare savings re-

lies on a vibrant industry and an adequately funded FDA. Therefore, Congress is urged to provide the FDA with a 15 percent increase to address this backlog.

Conclusion

The National MS Society thanks the Committee for the opportunity to provide written testimony and our recommendations for fiscal year 2012 appropriations. The agencies and programs we have discussed are of vital importance to people living with MS and we look forward to continuing to working with the Committee to help move us closer to a world free of MS.

PREPARED STATEMENT OF THE NATIONAL NETWORK TO END DOMESTIC VIOLENCE

Introduction

I am submitting testimony to request a targeted investment of \$196 million in the Family Violence Prevention and Services Act (FVPSA) and the Violence Against Women Act (VAWA) programs administered by the U.S. Department of Health and Human Services fiscal year 2012 budget (specific requests detailed below).

Labor, Health and Human Services Chairman Harkin, Ranking Member Shelby, Chairman Inouye, Ranking Member Cochran and distinguished members of the Appropriations Committee, thank you for this opportunity to submit testimony to the Committee on the importance of investing in FVPSA and VAWA programs. I sincerely thank the Committee for its ongoing support and investment in these life-saving programs. These investments help to bridge the gap created by an increased demand and a lack of available resources.

I am the President of the National Network to End Domestic Violence (NNEDV), the Nation's leading voice on domestic violence. We represent the 56 State and territorial domestic violence coalitions, including those in Iowa, Alabama, Hawaii and Mississippi, their 2,000 member domestic violence and sexual assault programs, as well as the millions of victims they serve. Our direct connection with victims and victim service providers gives us a unique understanding of their needs and the vital importance of continued Federal investments.

Incidence, Prevalence, Severity and Consequences of Domestic and Sexual Violence

The crimes of domestic and sexual violence are pervasive, insidious and life-threatening. Nearly one in four women are beaten or raped by a partner during adulthood¹ and 2.3 million people are raped and/or physically assaulted by a current or former spouse or partner each year.² One in six women and 1 in 33 men have experienced an attempted or completed rape.³ Of course the most heinous of these crimes is murder. Every day in the United States, an average of three women are killed by a current or former intimate partner.⁴ In 2005 alone, 1,181 women were murdered by an intimate partner in the United States⁵ and approximately one-third of all female murder victims are killed by an intimate partner.⁶

The cycle of intergenerational violence is perpetuated as children are exposed to violence. Approximately 15.5 million children are exposed to domestic violence every year.⁷ One study found that men exposed to physical abuse, sexual abuse and adult domestic violence as children were almost 4 times more likely than other men to have perpetrated domestic violence as adults.⁸

In addition to the terrible cost domestic and sexual violence have on the lives of individual victims and their families, these crimes cost taxpayers and communities. In fact, the cost of intimate partner violence exceeds \$5.8 billion each year, of which

¹ AU.S. Department of Justice, National Institute of Justice and Centers for Disease Control and Prevention. (July 2000). *Extent, Nature, and Consequences of Intimate Partner Violence: Finding from the National Violence Against Women Survey*. Washington, DC. Tjaden, Pl., & Thoennes, N.

² Ibid.

³ U.S. Department of Justice, *Prevalence, Incidence, and Consequences of Violence Against Women: Findings from the National Violence Against Women Survey* (1998).

⁴ Bureau of Justice Statistics (2008). *Homicide Trends in the U.S. from 1976–2005*. Dept. of Justice.

⁵ Ibid.

⁶ Bureau of Justice Statistics, *Homicide Trends from 1976–1999*. (2001)

⁷ McDonald, R., et al. (2006). "Estimating the Number of American Children Living in Partner-Violence Families." *Journal of Family Psychology*, 30(1), 137–142.

⁸ Greenfield, L. A. (1997). *Sex Offences and Offenders: An Analysis of Date on Rape and Sexual Assault*. Washington, DC. Bureau of Justice Statistics, U.S. Department of Justice.

\$4.1 billion is for direct medical and mental healthcare services.⁹ Research shows that intimate partner violence costs a health insurance plan \$19.3 million each year for every 100,000 women between the ages of 18 and 64 who are enrolled.¹⁰ Domestic violence costs U.S. employers an estimated \$3 to \$13 billion annually.¹¹ Between one-quarter and one-half of domestic violence victims report that they lost a job, at least in part, due to domestic violence.

Despite this grim reality, we know that when a coordinated response is developed and immediate, essential services are available, victims can escape from life-threatening violence and begin to rebuild their shattered lives. Funding these programs is fiscally sound, as they save lives, prevent future violence, keep families and communities safe, and save our Nation money. While Federal funding cannot meet all the needs of victims, it leverages State, private and local dollars to provide consistent funding streams to lifesaving services. To address unmet needs and build upon its successes, VAWA/FVPSA should receive targeted investments in fiscal year 2012.

Family Violence Prevention and Services Act (FVPSA) (Administration for Children and Families)—\$140 million request. Since its passage in 1984 as the first national legislation to address domestic violence, FVPSA has remained the only funding directly for shelter programs. For more than 25 years, FVPSA has made substantial progress toward ending domestic violence. Despite the progress and success brought by FVPSA, a strong need remains for FVPSA-funded services for victims.

Domestic violence is more than a crime—it is a public health issue. To address this issue, there are more than 2,000 community-based domestic violence programs for victims and their children (approximately 1,500 of which are FVPSA-funded through State formula grants). These programs offer services such as emergency shelter, counseling, legal assistance, and preventative education to millions of women, men and children annually and are at the heart of our Nation's response to domestic violence.¹² These effective programs save and rebuild lives. A recently released multi-state study conclusively shows that the Nation's domestic violence shelters are addressing victims' urgent and long-term needs and are helping victims protect themselves and their children. This same study indicated that, if shelters did not exist, the consequences for victims would be dire, including "homelessness, serious losses including children [or] continued abuse or death."

According to a report by the National Network to End Domestic Violence, in one day in 2010, more than 70,000 victims of domestic violence received services, of which 50 percent found refuge in emergency shelters and transitional housing. Of the 23,743 victims in emergency shelter that day, more than 50 percent were children. However, on that same day, more than 9,500 requests for services by adults and children were unmet due to lack of funding.

Addressing the Needs of Children and Breaking the Intergenerational Cycle of Violence

In addition to providing crisis services to adults fleeing violence, FVPSA helps to break the intergenerational cycle of violence. Approximately one-half to two-thirds of residents in domestic violence shelters are children. In 2010, Congress reauthorized FVPSA that included a newly authorized program, Specialized Services for Abused Parents and Their Children. In fiscal year 2010, Congress appropriated nearly \$131 million for FVPSA, which for the first time triggered spending dedicated to specialized service for children who witness domestic violence.

The newly authorized Children's program is an important step in the Federal Government's response to domestic violence. It will build an evidence base for services, strategies, advocacy and interventions for children and youth exposed to domestic violence. Although many domestic violence programs currently serve children, this program will expand the capacity of domestic violence programs to address the needs of children and adolescents coming into emergency shelters. To ensure that children's needs are met in the community, the program will create state-wide and local improvements in systems and responses to children and youth exposed to domestic violence. Finally, the program will eventually lead to nationwide dissemination of lessons learned and strategies for implementation in communities across the country.

⁹National Center for Injury Prevention and Control. Costs of Intimate Partner Violence Against Women in the United States. Atlanta (GA): Centers for Disease Control and Prevention; 2003.

¹⁰Ibid.

¹¹Bureau of National Affairs Special Rep. No. 32, Violence and Stress: The Work/Family Connection 2 (1990); Joan Zorza, Women Battering: High Costs and the State of the Law, Clearinghouse Rev., Vol. 28, No. 4, 383, 385; Supra, see endnote 10.

¹²National Coalition Against Domestic Violence, Detailed Shelter Surveys (2001).

Currently, four States have received modest funding grants to build upon their work and lay groundwork for the national project. The New Jersey Coalition for Battered Women will expand an established model program, Peace: A Learned Solution (PALS), which provides children ages 3 through 17 with creative arts therapy to help them heal from exposure to domestic violence. The Wisconsin Coalition Against Domestic Violence will launch the Safe Together Project, which will increase the capacity of Wisconsin domestic violence programs, particularly those serving under-represented or culturally specific populations, to support non-abusing parents and mitigate the impact of exposure to domestic violence on their children. The Alaska Network on Domestic Violence and Sexual Assault will improve services and responses to Alaska's families by addressing the lack of coordination between domestic violence agencies and child welfare systems. Together, grantees will serve as leaders for expanding a broader network for support; developing evidence-based interventions for children, youth and parents exposed to domestic violence; and building national implementation strategies that will lead to local improvements in domestic violence program and community systems interventions.

Unfortunately, the rescission in the final fiscal year 2011 budget cut all funding for the new children's program. If the funding is not restored to at least \$140 million in fiscal year 2012, these innovative and cost-saving projects will be in jeopardy.

The Increased Need for Funding

Many programs across the country use their FVPSA funding to keep the lights on and their doors open. We cannot overstate how important this is: victims must have a place to flee to when they are escaping life-threatening violence. Countless shelters across the country would not be able to operate without FVPSA funding. As increased training for law enforcement, prosecutors and court officials has greatly improved the criminal justice system's response to victims of domestic violence, there is a corresponding increase in demand for emergency shelter, hotlines and supportive services. Additionally, demand has increased as a result of the economic downturn and victims with fewer personal resources become increasingly vulnerable. Since the economic crisis began, three out of four domestic violence shelters have reported an increase in women seeking assistance from abuse.¹³ As a result, shelters overwhelmingly report that they cannot fulfill the growing need for these services.

In the current economic climate, the demand for domestic violence services has increased precisely at the time when programs are struggling to maintain State and private funding to meet the demand. In fact, the National Domestic Violence Census found that in 2010, 1,441 (82 percent) domestic violence programs reported a rise in demand for services, while at the same time, 1,351 (77 percent) programs reported a decrease in funding.¹⁴ Between 2009 and 2010, domestic violence programs laid off or did not replace nearly 2,000 staff positions including counselors, advocates and children's advocates, and a number of shelters around the country closed. In 2009, although FVPSA-funded domestic violence programs provided shelter and nonresidential services to more than 1 million victims, an additional 167,069 requests for lifesaving shelter went unmet due to lack of capacity. In Alabama, the problem reflects the rest of the Nation. More than 30 percent of Alabama programs reported that they did not have enough funding for needed programs and services and 17 percent reported no available beds or funding for hotels. In Iowa, nine programs statewide have already closed their doors due to funding shortages and many other programs have been forced to reduce the types of services provided, including eliminating child advocate positions and prevention programs dedicated to breaking the cycle of violence.

We cannot allow the gap between available resources and the desperate need of victims to widen. For those individuals who are not able to find safety, the consequences can be extremely dire, including continued exposure to life-threatening violence or homelessness. It is absolutely unconscionable that victims cannot find safety for themselves and their children due to a lack of adequate investment in these services. In order to meet the immediate needs of victims in danger and to continue to break the intergenerational cycle of violence, FVPSA funding must be increased to at least \$140 million in fiscal year 2012.

¹³ Mary Kay's Truth About Abuse. Mary Kay Inc. (May 12, 2009).

¹⁴ Domestic Violence Counts 2010: A 24-Hour census of domestic violence shelters and services across the United States. The National Network to End Domestic Violence. (Jan. 2011).

*Additional Requests**National Domestic Violence Hotline (Administration for Children and Families)—\$5 million request*

For the past 15 years the Hotline has provided 24-hour, toll-free and confidential services, immediately connecting callers to local service providers. During this economic downturn, crisis calls to the Hotline have increased. Additionally, to address the specific needs of dating violence victims, the Hotline launched the National Dating Abuse Helpline, which has seen increased traffic recently.

DELTA Prevention Program (Centers for Disease Control and Injury Prevention)—\$6 million request

DELTA is one of the only sources of funding for domestic violence prevention work. The program supports statewide projects that integrate primary prevention principles and practices into local coordinated community responses that address and reduce the incidence of domestic violence. Currently, DELTA funds 56 Coordinated Community Response Coalitions nationwide. In the first 3 years that DELTA funded these projects, the primary prevention activities in communities increased ten-fold. Nineteen States, including Alabama and Iowa, are currently funded as DELTA Prep states by the Robert Wood Johnson Foundation. Without additional DELTA funding, these States, ready in 2012 to fully participate, may not be able to access CDC funding.

Rape Prevention and Education (RPE) (Centers for Disease Control and Injury Prevention)—\$42.6 million request

This VAWA program administered through CDC strengthens national, State and local sexual violence prevention efforts and the operation of rape crisis hotlines. RPE funding provides formula grants to States and territories to support rape prevention and education programs conducted by rape crisis centers, State sexual assault coalitions and other public and private nonprofit entities. Funding also supports the National Sexual Violence Resource Center, which provides up-to-date information regarding sexual violence to policymakers, Federal and State agencies, college campuses, sexual assault and domestic violence coalitions, local programs, the media, and the general public. Despite its critical work, RPE has faced funding decreases since fiscal year 2006.

Violence Against Women Health Initiative (Office of Women's Health)—\$2.3 million request

This eight State and two tribe initiative promotes public health programs that integrate domestic and sexual violence assessment and intervention into basic care. Congress has included the program in the last 3 fiscal years, but after the first year, the funding has not been on top of the agency's overall budget. As a result, HHS has been forced to cut other violence prevention activities to fund the program. Funding is needed to identify best practices, conduct general evaluation and disseminate the results to the field so that victims nationwide can benefit.

Conclusion

Together, these LHHS programs work to prevent and end domestic and sexual violence. While our country has made continued investments in the criminal justice response to these heinous crimes, we need an equal investment in the human service, public health and prevention response in order to holistically address and end violence against women. We know that our Nation is facing a difficult financial time and that there is pressure to reduce spending. Investments in these vital, cost-effective programs, however, help break the cycle of violence, reduce related social ills and will save our Nation money now and in the future.

PREPARED STATEMENT OF THE NATIONAL POSTDOCTORAL ASSOCIATION

Thank you for this opportunity to testify in regard to the fiscal year 2012 funding for the National Institutes of Health (NIH). We are writing today in regard to support for postdoctoral scholars, specifically in support of the 4-percent increase in the NIH Ruth L. Kirschstein National Research Service Awards (NRSA) training stipends, as requested in the President's budget.

Background: Postdocs are the Backbone of U.S. Science and Technology

According to estimates by The National Science Foundation (NSF) Division of Science Resource Statistics, there are approximately 89,000 postdoctoral scholars in

the United States¹. The NIH and the NSF define a “postdoc” as: An individual who has received a doctoral degree (or equivalent) and is engaged in a temporary and defined period of mentored advanced training to enhance the professional skills and research independence needed to pursue his or her chosen career path. The number of postdocs has been steadily increasing. The incidence of individuals taking postdoc positions during their careers has risen, from about 25 percent of those with a pre-1972 doctorate to 46 percent of those receiving their doctorate in 2002–05². Moreover, the number of science and engineering doctorates awarded each year is steadily rising with doctorates awarded in the medical/life sciences almost tripling between 2003 and 2007³.

Postdocs are critical to the research enterprise in the United States and are responsible for the bulk of the cutting edge research performed in this country. Consider the following:

- According to the National Academies, postdoctoral researchers “have become indispensable to the science and engineering enterprise, performing a substantial portion of the Nation’s research in every setting.”⁴
- Postdoctoral training has become a prerequisite for many long-term research projects.⁵ In fact, the postdoc position has become the de facto next career step following the receipt of a doctoral degree in many disciplines.
- The retention of women and under-represented groups in biomedical research depends upon their successful and appropriate completion of the postdoctoral experience.
- Postdoctoral scholars carry the potential to solve many of the world’s most pressing problems; they are the principal investigators of tomorrow.

Unfortunately, postdocs are routinely exploited. They are paid a low wage relative to their years of training and are often ineligible for workman’s compensation, disability insurance, paid maternity or paternity leave, employer-sponsored medical benefits, and retirement accounts.

The National Postdoctoral Association (NPA) advocates for policies that support and enhance postdoctoral training. NPA members advocate for policy change on the national level and also within the research institutions that host postdoctoral scholars. To date, more than 150 institutions have adopted portions of the NPA’s recommended practices, but low compensation remains one of the serious issues faced by the postdoctoral community.

Problem: NRSA Stipends are Low and Don’t Meet Cost-of-Living Standards; For Better or Worse, Postdoc Compensation is Based on NRSA Stipends

The NIH leadership has been aware that the NRSA training stipends are too low since 2001, after the publication of the results of the National Academy of Sciences (NAS) study, *Addressing the Nation’s Changing Needs for Biomedical and Behavioral Scientists*. In response, the NIH pledged (1) to increase entry-level stipends to \$45,000 by raising the stipends at least 10 percent each year and (2) to provide automatic cost-of-living increases each year thereafter to keep pace with inflation. Most recently, the 2011 NAS study, *Research Training in the Biomedical, Behavioral, and Clinical Research Sciences*, called for, among other recommendations, increased funding to support more NRSA positions and to fulfill the NIH’s 2001 commitment to increase pre-doctoral and postdoctoral stipends.

Without sufficient appropriations from Congress, the NIH has not been able to fulfill its pledge. In 2007, the stipends were frozen at 2006 levels and since then have not been significantly increased. The stipends were increased by 1 percent each year in 2009 and 2010 and by 2 percent in 2011. The 2011 entry-level training stipend remains low, at \$38,496, the equivalent of a GS-8 position in the Federal Government (NIH Statement NOT-OD-10-047), despite the postdocs’ advanced degrees and specialized technical skills. Furthermore, this stipend remains far short of the promised \$45,000. Certainly, it is not reflective of any cost-of-living increases (please see Figure 1).

¹ National Science Foundation Division of Science Resource Statistics. (January 2010). *Science and engineering indicators 2010*. Arlington, VA: National Science Board.

² Ibid.

³ Ibid.

⁴ COSEPUP. (June 2001). *Enhancing the postdoctoral experience for scientists and engineers*. Washington, D.C.: National Academy Press. p. 10.

⁵ COSEPUP. (June 2001). *Enhancing the postdoctoral experience for scientists and engineers*. Washington, D.C.: National Academy Press. p. 11.

**Actual vs. Cost of Living Allowance (COLA)
Projected Stipends**

Created by Jennifer Hobin, Ph.D.

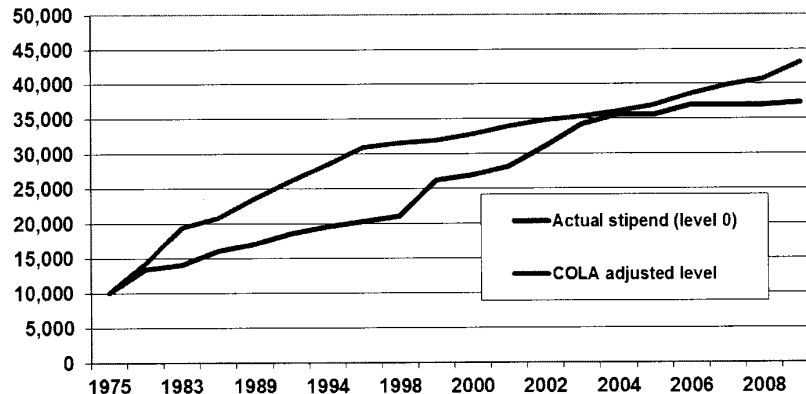


FIGURE 1

It is not only the NRSA fellows who remain undercompensated; the impact of the low stipends extends beyond the NRSA-supported postdocs. The NPA's research has shown that the NIH training stipends are used as a benchmark by research institutions across the country for establishing compensation for postdoctoral scholars. Thus, an unintended consequence is that institutions undercompensate all of their postdocs, who must then struggle to make ends meet, which in turn affects their productivity and undermines their efforts to solve the world's most critical problems. Additionally, many are leaving their research careers behind because of the low compensation. In order to keep the "best and the brightest" scientists in the U.S. research enterprise, the NPA believes that it is crucial that Congress appropriate funding for the 4-percent increase in training stipends, as a moderate yet substantial step toward reaching the recommended entry-level stipend of \$45,000.

Solution: Keep the NIH's Original Promise to Raise the Minimum Stipends

We ask the Subcommittee to appropriate \$794 million for the 4-percent stipend increase, as requested in the President's proposed budget (http://www.nih.gov/about/director/budgetrequest/NIH_BIB_020911.pdf): As part of the President's initiative in fiscal year 2012 to emphasize support for science, technology, engineering, and mathematics (STEM) education programs, the budget proposes a 4 percent stipend increase for predoctoral and postdoctoral research trainees supported by NIH's Ruth L. Kirschstein National Research Service Awards program. A total of \$794 million is requested in fiscal year 2012 for this training program. The proposed increase in stipends will allow NIH to continue to attract high quality research trainees that will be available to address the Nation's future biomedical, behavioral, and clinical research needs.

The NPA believes it is fair, just, and necessary to increase the compensation provided to these new scientists, who make significant contributions to the bulk of the research discovering cures for disease and developing new technologies to improve the quality of life for millions of people in the United States. Please do not hesitate to contact us for more information. Thank you for your consideration.

PREPARED STATEMENT OF THE NATIONAL PRIMATE RESEARCH CENTERS

The Directors of the eight National Primate Research Centers (NPRCs) respectfully submit this written testimony for the record to the Senate Appropriations Subcommittee on Labor, Health and Human Services, Education and Related Agencies. The NPRCs appreciate the commitment that the Members of this Subcommittee have made to biomedical research through your support for the National Institutes of Health (NIH) and recommend that you provide \$31.987 billion for NIH in fiscal year 2012, which represents a 3.4 percent increase above the fiscal year 2011 level. Within this proposed increase the NPRCs also respectfully request that the Subcommittee provide strong support for the NPRC P51 (base grant) program, which

is essential for the operational costs of the eight NPRCs. This support would help to ensure that the NPRCs and other animal research resource programs continue to serve effectively in their role as a vital national resource.

The mission of the National Primate Research Centers is to use scientific discovery and nonhuman primate models to accelerate progress in understanding human diseases, leading to better health. The NPRCs collaborate as a transformative and innovative network to support the best science and act as a resource to the biomedical research community as efficiently as possible. There is an exceptional return on investment in the NPRC program; \$10 is leveraged for every \$1 of research support for the NPRCs. It is important to sustain funding for the NPRC program and the NIH as a whole to continue to grow and develop the innovative plan for the future of NIH.

NPRCs Contributions to NIH Priorities

The NPRCs activities are closely aligned with NIH's priorities. In fact, NPRC investigators conduct much of the Nation's basic and translational nonhuman primate research, facilitate additional vital nonhuman primate research that is conducted by hundreds of investigators from around the country, provide critical scientific expertise, train the next generation of scientists, and advance cutting-edge technologies. The NPRCs currently are engaged with NIH staff in a comprehensive strategic planning process to further enhance the capabilities of the NPRCs to serve as a resource across all NIH institutes and centers. The NPRC consortium strategic plan has as its center and driving force the scientific priorities that drive translational work into better interventions and diagnostics for improved human health. Outlined below are a few of the overarching goals of the plan, including specifics of how the NPRCs are striving to achieve these through programs and activities across the centers.

Advance Translational Research Using Animal Models.—Nonhuman primate models bridge the divide between basic biomedical research and implementation in a clinical setting. Currently, seven of the eight NPRCs are affiliated and collaborate with NIH Clinical and Translational Science Awards (CTSA) program through their host institution. Specifically, the nonhuman primate models at the NPRCs often provide the critical link between research with small laboratory animals and studies involving humans. As the closest genetic model to humans, nonhuman primates serve in the development process of new drugs, treatments, and vaccines to ensure safe and effective use for the Nation's public.

Strengthen the Research Workforce.—The success of the Federal Government's efforts in enhancing public health is contingent upon the quality of research resources that enable scientific research ranging from the most basic and fundamental to the most highly applied. Biomedical researchers have relied on one such resource—the NPRCs—for nearly 50 years for research models and expertise with nonhuman primates. The NPRCs are highly specialized facilities that foster the development of nonhuman primate animal models and provide expertise in all aspects of nonhuman primate biology. NPRC facilities and resources are currently used by over 2,000 NIH funded investigators around the country.

The NPRCs are also supportive of getting students interested in the biomedical research workforce pipeline at an early age. For example, the Yerkes NPRC supports a program that connects with local high schools and colleges in Atlanta, Georgia, and invites students to participate in research projects taking place at their field station location.

Offer Technologies to Advance Translational Research and Expand Informatics Approaches to Support Research.—The NPRCs have been leading the development of a new Biomedical Informatics Research Network (BIRN) for linking brain imaging, behavior, and molecular informatics in nonhuman primate preclinical models of neurodegenerative diseases. Using the cyberinfrastructure of BIRN for data-sharing, this project will link research and information to other primate centers, as well as other geographically distributed research groups.

Translational Science at the NPRCs

Animal models are an essential tool for translating basic biomedical research to treatments and cures for patients, and the NPRCs are a national resource instrumental to this effort. The network of the eight NPRCs collaborates across many disciplines and institutions, with the goal of advancing biomedical knowledge to understand disease and improve human and animal health. Below are specific examples of translational research conducted at each of the eight NPRCs.

In work conducted at the California National Primate Research Center, Immunoglobulin G (IgG) antibodies purified from mothers of children with autism and mothers of typically developing children were injected into pregnant rhesus monkeys. The offspring were then evaluated both neurologically and behaviorally.

Offspring of mothers who received IgG from mothers of children with autism demonstrated significantly higher levels of repetitive behaviors than the offspring who received control antibodies. There are currently no diagnostic tests for autism. This research identifies one potential autoimmune cause of autism. Moreover, detection of the maternal autoantibodies may become an early diagnostic test for increased risk of having a child with autism. This research, which relied on treating pregnant rhesus monkeys, could not have been conducted without the facilities provided by the national primate center.

Rhesus monkeys are widely used as animal models across many fields of biomedical research because of their genetic, physiological, behavioral, and anatomical similarities to humans. Scientists at the New England National Primate Research Center are taking advantage of the genetic similarity between rhesus monkeys and humans to create the first monkey model of alcoholism genetics. Recent studies in human alcoholics who are treated with naltrexone, a leading medication for alcohol dependence, have shown that the medication works better in people who have a specific genetic variant in the OPRM1 gene. Scientists at the New England NPRC identified a similar genetic change in the rhesus monkey OPRM1 gene, and have shown that monkeys with the genetic change not only drink more alcohol but also have a comparable genetically determined response to naltrexone to that seen in some human alcoholics. This animal model gives scientists a new way to create personalized medications for the treatment of alcoholism.

A new technique developed by a research team at the Oregon National Primate Research Center offers a way for women with mitochondrial diseases to have their own children without passing on defective genetic material. According to the scientists, defective genes in mitochondria can be passed to children at a frequency of 1 in 4,000 births and can lead to a variety of diseases. Symptoms of these potentially fatal illnesses include dementia, movement disorders, blindness, hearing loss, and problems of the heart, muscle, and kidney. Following this successful study in a nonhuman primate model, scientists believe that the technique could be applied quickly to humans to prevent devastating diseases.

In 2005, researchers were looking for an animal model in which to test a prototype device which might ameliorate degenerative disc disease, a major cause of disability in working-age adults. The baboon was chosen as an appropriate animal model for safety testing of the new device because of its upright posture and the high magnitude of forces placed on the vertebral column during the baboon's natural movement. After a small pilot study, two subsequent pre-clinical studies were performed at the Southwest National Primate Research Center. This was an international effort in which specialists from Denmark, Canada, and the United Kingdom visited the Primate Center on numerous occasions to participate in the studies. The data from these studies along with data from human clinical trials are now being assembled for submission to the U.S. Food and Drug Administration for approval to use the artificial disc in the United States as an alternative for the treatment of degenerative lumbar spinal disease.

Testing the safety and efficacy of potential compounds in nonhuman primates is virtually essential to advancing microbicide candidates to clinical trials to prevent HIV transmission. There are far too many microbicide candidates in development for all of them to be tested in human trials. Over the years, the Tulane National Primate Research Center has facilitated microbicide studies in nonhuman primates that have led to human clinical trials, and have been the only successful predictor of success or failure of compounds in these trials. Furthermore, candidates that were not sufficiently tested in nonhuman primates prior to human trials were shown to fail, and later studies, once performed in macaques, confirmed they would have been predictive of failure.

Studies completed at the Tulane NPRC have resulted in Merck releasing one of these compounds to the International Partnership for Microbicides (IPM) for microbicide development and human clinical testing. Based on the positive results in macaque studies, the IPM also has been granted license to pursue topical development of Pfizer's Maraviroc as a microbicide. Nonhuman primate testing has resulted in a wealth of information that has prevented expensive clinical trials in humans that would have otherwise been fruitless.

Recovery of function after stroke, traumatic brain injury or spinal cord injury is a significant medical challenge for millions of patients in the United States. A promising new treatment for many of these disabled survivors is an implantable recurrent brain-computer interface (R-BCI). The Washington National Primate Research Center developed R-BCI, a "neurochip" that records neural activity from the brain and transforms that activity into stimuli delivered to the brain, spinal cord, or muscles during free behavior. R-BCI technology has the clinical potential to aid patients paralyzed by ALS or spinal cord injury to regain some motor control directly from

cortical cells and may also be used to strengthen weak connections impaired by stroke.

Researchers and physicians are getting closer to a novel diagnostic test for polycystic ovary syndrome (PCOS), which has staggering adverse physiological, psychological, and financial consequences for women's reproductive health. Scientists at the Wisconsin National Primate Research Center are studying the profile of metabolites in both monkey and patient samples of blood, urine, sweat, and breath molecules to identify signals in the body's internal chemistry that are consistent with the syndrome. From the vast pool of metabolites in their samples, they have found a handful that rise to the surface as indicators of PCOS. These telltale molecules could become the basis for the first-ever diagnostic test for the syndrome.

A recent study based on work conducted at the Yerkes National Primate Research Center with nonhuman primates illustrates the promise of the Visual Paired Comparison (VPC) task for the detection of mild memory impairment associated with Alzheimer's disease (AD). To investigate this possibility, the Yerkes NPRC recently extended their collaborations to include the Department of Computer Sciences at Emory University. The results show that eye movement characteristics including fixation duration, saccade length and direction, and re-fixation patterns can be used to automatically distinguish impaired and normal subjects. Accordingly, this generalized approach has proven useful for improving early detection of AD, and may be applied, in combination with other behavioral tasks, to examine cognitive impairments associated with other neurodegenerative diseases. Researchers at the Yerkes NPRC have developed two patents based on this work.

The Need for Facilities Support

The NPRC program is a vital resource for enhancing public health and spurring innovative discovery. In an effort to address many of the concerns within the scientific community regarding the need for funding for infrastructure improvements, the NPRCs support the continuation of a robust construction and instrumentation grant program at NIH.

Animal facilities, especially primate facilities, are expensive to maintain and are subject to abundant "wear and tear." In prior years, funding was set aside that fulfilled the infrastructure needs of the NPRCs and other animal research facilities. The NPRCs ask the Subcommittee to provide strong support for construction and renovation of animal facilities through C06 and G20 programs. Without proper infrastructure, the ability for animal facilities, including the NPRCs, to continue to meet the high demand of the biomedical research community will be unattainable.

Thank you for the opportunity to submit this written testimony and for your attention to the critical need for primate research and the continuation of infrastructure support, as well as our recommendations concerning funding for NIH in the fiscal year 2012 appropriations bill.

PREPARED STATEMENT OF THE NATIONAL PSORIASIS FOUNDATION

INTRODUCTION AND OVERVIEW

The National Psoriasis Foundation (the Foundation) appreciates the opportunity to submit written public witness testimony regarding fiscal year 2012 Federal funding for psoriasis and psoriatic arthritis data collection and research. The Foundation is the largest psoriasis patient advocacy organization and charitable funder of psoriatic disease research worldwide, and has a primary mission of finding a cure for psoriasis and psoriatic arthritis. Psoriasis, the Nation's most prevalent autoimmune disease, affecting as many as 7.5 million Americans, is a noncontagious, chronic, inflammatory, painful and disabling disease for which there is no cure. It appears on the skin, most often as red, scaly patches that itch, can bleed and require sophisticated medical intervention. Up to 30 percent of people with psoriasis also develop potentially disabling psoriatic arthritis that causes pain, stiffness and swelling in and around the joints. There are other serious risks associated with psoriasis—for example, diabetes, cardiovascular disease, stroke and some cancers. Of serious concern is that, beyond its terrible physical and psychosocial toll on individuals, psoriasis also costs the Nation \$11.25 billion annually.

The Foundation works with the research community and policymakers at all levels of government to advance policies and programs that will reduce and prevent suffering from psoriasis and psoriatic arthritis. In 2009, after examining existing scientific literature, clinical practice and other components of psoriasis and psoriatic arthritis research and care, the Foundation's medical and scientific advisors recommended the creation of a federally organized, public health research program for psoriasis and psoriatic arthritis to collect the information necessary to address the

key scientific questions in the study and treatment of psoriatic disease. Responding to this recommendation, recognizing the significant economic and social costs of psoriasis and psoriatic arthritis and acknowledging the sizeable gap in the understanding of these devastating conditions, in fiscal year 2010, Congress provided \$1.5 million to the Centers for Disease Control and Prevention (CDC) to commence the first-ever Government effort to collect data on psoriasis and psoriatic arthritis. Following this initial investment, in its fiscal year 2011 Labor, Health and Human Services, Education (LHHS) funding bill, the Senate provided a second allocation of \$1.5 million to continue these critical public health efforts. While that measure was not enacted, we want to thank you and your colleagues for recognizing the importance of psoriasis data collection and ask for your support again in fiscal year 2012.

Since the initial appropriation, considerable progress has been made in developing this data collection program in a thoughtful and deliberate manner, and we commend CDC for its excellent methodology and undertaking of this important effort. Thus far, Federal investment in this effort has allowed the CDC, along with other Federal stakeholders, to identify the key gaps in psoriatic disease data, including: prevalence, age of onset, health-related quality of life, healthcare utilization, burden of disease (employment, work, etc.), direct and indirect costs, health disparities (age, gender, racial and ethnic), comorbidities and an understanding of the course of the disease over time. To uncover these important public health issues, in 2010, CDC researchers collaborated with the Foundation's scientific and medical advisors to establish a process by which a common basis for defining and diagnosing psoriasis will be created and validated. This work, in turn, will provide the insight, information and tools CDC researchers need to determine the key psoriasis and psoriatic arthritis public health questions to be pursued.

While the Foundation acknowledges the fiscal realities currently facing Congress and this Nation, scientific discovery, at this moment, is poised to advance the understanding and treatment of psoriasis and psoriatic arthritis. As such, we respectfully request that Congress continue to support this important initiative by appropriating level funding, \$1.5 million, in fiscal year 2012, to enable CDC to refine and implement the psoriasis and psoriatic data collection process that has been defined with previous funding. With fiscal year 2012 funding, CDC researchers will be able to build upon the initial investment and integrate psoriasis and psoriatic arthritis questions into existing federally funded public health surveys, allowing economies of scale and leveraging scarce resources to maximum their utility. The information gleaned from this effort will help improve treatments and disease management, identify new pathways for future research and drug development and inform efforts to reduce the burden of disease on patients, their families and society in general.

In addition, the Foundation urges the Subcommittee to support robust fiscal year 2012 funding for the National Institutes of Health (NIH). Sustaining Federal investment in biomedical research will help support new investigator-initiated research grants for genetic, clinical and basic research related to the understanding of the cellular and molecular mechanisms of psoriasis and psoriatic arthritis. Epidemiologic research at CDC, coupled with biomedical investigations through NIH, will help further the Nation's understanding of psoriasis and psoriatic arthritis and contribute to the development of better therapies, improved treatments and disease management and identification of ways in which comorbid conditions (e.g., heart attack, cancer and diabetes) can be prevented or mitigated, in turn, helping to save money and lives.

THE IMPACT OF PSORIASIS AND PSORIATIC ARTHRITIS ON THE NATION

Psoriasis requires steadfast treatment and lifelong attention, especially since it most often strikes between ages 15 and 25. People with psoriasis also have significantly higher healthcare resource utilization, which costs more than that for the general population. Of serious and increasing concern is mounting evidence that people with psoriasis are at elevated risk for myriad other serious, chronic and life-threatening conditions, including cardiovascular disease, diabetes, stroke and some cancers. A higher prevalence of atherosclerosis, chronic obstructive pulmonary disease, Crohn's disease, lymphoma, metabolic syndrome and liver disease are found in people with psoriasis, as compared to the general population. In addition, people with psoriasis experience higher rates of depression and anxiety, and people with severe psoriasis die 4 years younger, on average, than people without the disease.

Despite some recent breakthroughs, many people with psoriasis and psoriatic arthritis remain in need of effective, safe, long-term and affordable therapies to allow them to function normally without both physical and emotional pain. Due to the nature of the disease, patients often have to cycle through available treatments, and while there are an increasing number of methods to control the disease, there is no

cure. Many of the existing treatments can have serious side effects and can pose long-term risks for patients (e.g., suppress the immune system, deteriorate organ function, etc.). The lack of viable, long-term methods of control for psoriasis can be addressed through Federal commitment to epidemiological, genetic, clinical and basic research. NIH and CDC research, taken together, hold the key to improved treatment of these diseases, better diagnosis of psoriatic arthritis and eventually a cure.

THE ROLE OF CDC IN PSORIASIS AND PSORIATIC ARTHRITIS RESEARCH

Despite our increased understanding of the autoimmune underpinnings of psoriasis and its treatments, there is a dearth of population-based epidemiology data on psoriatic disease. The majority of existing studies of psoriasis are based on case reports, case series and cross-sectional studies, which are likely biased toward more severe disease. Several analytical studies have been performed to identify potentially modifiable risk factors (e.g., smoking, diet, etc.) and some have yielded conflicting, or inconsistent, results. Most case-control studies looking for risk factors have been hospital-based, or specialty clinic-based, and again may be biased toward more severe disease, limiting their value for the larger population with psoriasis. Broadly representative population-based studies of psoriasis reflecting the full spectrum of disease are lacking and needed because there are still wide gaps in our knowledge and understanding of psoriatic disease.

The CDC's psoriatic data collection effort will help to provide scientists and clinicians with critical information to further their understanding of: (a) how early intervention can prevent or delay the development of comorbid conditions; (b) what can trigger relapses and remissions; (c) some of the underlying causes of disease; (d) how differentiating lifestyle and other environmental triggers might lead to approaches that minimize exposure to these factors, thus reducing the incidence and severity of disease; and (e) best practice treatments, which in turn, would assist in streamlining appropriate patient care and help reduce the use of ineffective, unnecessary and costly treatments with challenging side effects.

PSORIASIS AND PSORIATIC ARTHRITIS RESEARCH AT NIH

It has taken nearly 30 years to understand that psoriasis is, in fact, not solely a disease of the skin, but also of the immune system. In recent years, scientists finally have identified some of the immune cells involved in psoriasis. The last decade has seen a surge in our understanding of these diseases, accompanied by new drug development. Scientists are poised, as never before, to make major breakthroughs.

Within the NIH, the National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS) is the principal Federal Government agency that currently supports psoriasis research. We commend NIAMS for its leadership role and very much appreciate its steadfast commitment to supporting psoriasis research. Additionally, we are pleased that research activities that relate to psoriasis or psoriatic arthritis also have been undertaken at the National Institute of Allergy and Infectious Diseases (NIAID), the National Cancer Institute (NCI), the National Center for Research Resources (NCRR) and the National Human Genome Research Institute (NHGRI); however, the Foundation maintains that many more NIH institutes and centers—such as the National Heart, Lung, and Blood Institute (NHLBI) and the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK)—have a role to play, especially with respect to the myriad comorbidities of psoriasis, as noted earlier. Although overall NIH funding levels improved for psoriasis research in fiscal year 2010, and funding was boosted through stimulus funding awards of \$3 million in fiscal year 2009 and (an estimated) \$2 million in fiscal year 2010, the Foundation remains concerned that total NIH funding generally is not keeping pace with psoriasis and psoriatic arthritis research needs. Our scientific advisors believe a strong Federal investment in genetic, immunological and clinical studies focused on understanding the mechanisms of psoriasis and psoriatic arthritis is needed.

Given the myriad factors involved in psoriatic disease and its comorbid conditions, the Foundation advocates increasing overall NIH funding, with a focus on the aforementioned institutes. We recognize and appreciate that the Nation faces significant budgetary challenges; however, we maintain that an increased investment in the Nation's biomedical research enterprise will help strengthen both the economy and our understanding of psoriasis and psoriatic arthritis.

CONCLUSION/SUMMARY

On behalf of the more than 7.5 million people with psoriasis and psoriatic arthritis, I want to thank the Committee for affording us the opportunity to submit written testimony regarding the fiscal year 2012 investments we believe are necessary

to ensure that our Nation adequately addresses the needs of individuals and families affected by psoriatic disease. By sustaining the Nation's biomedical research efforts at NIH, coupled with a specific allocation of \$1.5 million for the CDC's psoriasis data collection efforts, Congress will help ensure that the Nation makes progress in understanding the connection between psoriasis and its comorbid conditions; uncovering the biologic aspects of psoriasis and other risk factors that lead to higher rates of comorbid conditions; and identifying ways to prevent and reduce the onset of comorbid conditions associated with psoriasis.

Please feel free to contact the Foundation at any time; we are happy to be a resource to Subcommittee members and your staff. Again, we very much appreciate the Committee's attention to, and consideration of, our fiscal year 2012 requests.

PREPARED STATEMENT OF THE NATIONAL REACH COALITION

The National REACH Coalition represents more than 40 communities and coalitions in 22 States working to eliminate racial and ethnic health disparities and improve the health of Native American/Native Hawaiian, African American, Latino, and Asian/Pacific Islander populations and communities. The coalition is an outgrowth of the Racial and Ethnic Approaches to Community Health (REACH U.S.) 2010 initiative, launched in 1999 by the Centers for Disease Control and Prevention (CDC). REACH programs are embedded in communities with disproportionately higher rates of chronic disease, hospitalization, and premature death than other cities and counties across the country. They provide coordination and leadership for the advancement and translation of community-based participatory research into evidence-based practices, policies, and community engagement.

For the fiscal year 2012 funding cycle, the National REACH Coalition requests the Labor, Health and Human Services, Education and Related Agencies (Labor-HHS) Subcommittee to fully fund, at current levels, the CDC's REACH program as a discrete line item in CDC's National Center for Chronic Disease Prevention and Health Promotion or as a specific initiative within the Public Health and Prevention Trust.

The NRC gratefully acknowledges the strong bipartisan support that the Senate Labor-HHS Subcommittee has provided to the REACH U.S. program over the years. Working in communities that are among the hardest hit by the recession, REACH programs provide a cost effective strategy to improve health outcomes and close the health gap. We understand the purpose of the newly established Community Transformation Grants (CTG) program to address health disparities in addition to chronic disease. However, the severity of discrepancy in health conditions among REACH-serving populations requires specific and intentional interventions and it is not sufficient for this to occur only through the CTG program. The generalized approach offered by CTG has been used over the last several decades and has resulted in no significant reduction in health disparities. Research data support the conclusion that to effectively close the gap in health outcomes in our country, there remains a definitive need for a program committed solely to the elimination of racial and ethnic health disparities.

REACH programs have been successful in mobilizing community resources, addressing policy, systems, and environmental change, and creating a shared vision to achieve healthy communities for racial and ethnic minorities. REACH programs focus on a variety of health issues, most notably chronic diseases such as cardiovascular disease, diabetes, HIV/AIDS, and cancer, as well as the contributors to these diseases, which include smoking, low physical activity, obesity, poor screening rates, and lack of prevention and disease management activities. Chronic diseases account for the largest health gap among racial and ethnic minority populations and are the Nation's leading cause of morbidity and mortality, accounting for 70 percent of all deaths. Collectively, chronic diseases are responsible for 75 cents of every dollar spent on healthcare in the United States.

REACH U.S. programs are working hard to eliminate these health disparities and many have seen successful outcomes in their communities. REACH programs nationwide have engaged hundreds of local coalition members and improved the lives of thousands of program participants. As a result, REACH communities are testing, evaluating, and implementing practice and evidence-based interventions that reduce the human and financial cost of these preventable diseases and associated risk factors. REACH has achieved significant policy and/or systems change in public policy, healthcare and preventative services, and health education.

Some of our recent successes in program intervention and policy change include:

—In South Carolina, the REACH Charleston and Georgetown Diabetes Coalition reports that a 21 percent gap in blood sugar testing between African Americans

- and the general population has been virtually eliminated. Amputations among African-American males with diabetes have been reduced by over 33 percent.
- In Macon County, Alabama, the REACH Alabama Breast and Cervical Cancer Coalition reports that disparities in mammography screening between the general population and African American women decreased from 15 percent to 2 percent within 5 years.
 - In Lawrence, Massachusetts, Latino CEED: REACH New England improved 14 healthcare indicators and outcomes for over 3200 Latinos with diabetes over the past decade, including four indicators now on par with the U.S. general population. One significant improvement was the percentage of Latino patients whose blood sugar was controlled, increasing from 15 percent to 45 percent as a result of REACH interventions.
 - In New York City, Bronx Health REACH led local partners in the “1 percent Or Less” campaign to eliminate whole milk and reduce the availability of sweetened milk in NYC public schools, where 25 percent of children in elementary schools are obese. By eliminating whole milk, the NYC Department of Health and Mental Hygiene calculated that per student per year almost 5,960 calories and 619 grams of fat were eliminated, or more than one pound of weight per child per year.
 - In South Los Angeles, Community Health Councils, a REACH grantee, addressed the lack of healthy food options in a predominantly African American community by advocating for local policy changes. These included an incentive package to attract 3 new grocery stores and sit-down restaurants into vulnerable communities and the adoption of an ordinance by the city to prohibit new stand-alone fast food restaurants within one half mile of an existing fast food chain.

In addition to the individual community improvements, data from the REACH national behavioral risk factor survey show that the REACH program is having a significant impact in risk reduction and disease management across communities and program wide. In 11 REACH communities evaluated between 2003 and 2009, there was meaningful improvement for all races in 34 out of 48 health risk factors, which include smoking prevalence, diabetes management, vaccination, and physical activity. REACH has demonstrated for the first time at a significant level that the elimination of health disparities is a “winnable battle”.

The success of REACH communities in reducing health risk and improving patient compliance and disease management is particularly striking when compared to overall U.S. trends. Some recent data trends include:

- From 2001 to 2009, the smoking prevalence in REACH communities for Asian men decreased from 30.5 percent to 13.8 percent in contrast to the 16.9 percent of Asian men that smoke in the U.S. overall. Smoking prevalence in Hispanic men decreased from 28.8 percent to 17.6 percent in contrast to the 19 percent of Hispanic men that smoke in the U.S. overall.
- From 2001 to 2004, African Americans transitioned from being less likely to more likely than the general population to have their cholesterol checked.
- Health education interventions in REACH communities resulted in larger rates (as much as 66 percent) of improvement across racial and ethnic populations for smoking, physical activity, consumption of fruits and vegetables, etc., than national trends between 2001 and 2009.

In addition to improving health outcomes, REACH programs also build capacity in the communities in which they operate. REACH programs train community and coalition members to work at the grassroots level on health issues, which can lead to employment opportunities at local health centers or community outreach programs. REACH also builds the capacity of local organizations and institutions to better serve their communities by addressing disparities and distributing resources where they are most needed. REACH is broadening the field of public health by engaging the food retail industry, local parks and recreation departments, city and regional land use, planning, housing, and transportation agencies, as well as healthcare providers.

REACH communities across the United States have spent the last decade leveraging CDC funding with public private partnerships in order to effectively address health disparities. We have demonstrated through our research and our community programs that health disparities in racial and ethnic populations, once considered expected, are not intractable. Though we have made significant progress since REACH's inception, we could do a lot more. To move forward and eliminate health disparities, we must continue our work within underserved communities across the United States and build upon the successes achieved to date. Without continued funding for REACH programs, communities with high minority populations will continue to bear a disproportionate share of the national chronic disease

burden. This not only keeps vulnerable communities at an increased disadvantage, but drives up healthcare costs by requiring long-term and costly medical intervention to treat chronic diseases that may have been prevented or better managed.

The success and cost effectiveness of the REACH program would suggest it both practical and fiscally prudent to increase funding for the program to expand into additional communities across the country. However, given the current budget constraints we strongly urge the Committee to fully fund, at current levels, the CDC's REACH program in a discrete line item in CDC's National Center for Chronic Disease Prevention and Health Promotion or as a specific initiative within the Public Health and Prevention Trust. By doing so, we can continue our work in underserved communities and achieve marked improvements in the health of all Americans. We believe that our efforts will help to decrease the approximately 83,000 deaths that occur each year as a result of racial and ethnic health disparities, decrease the estimated \$60 billion a year we spend in direct healthcare expenditures as a result of these disparities, and improve health access, quality, and outcomes for many people.

We thank you for this opportunity to present our views to this Subcommittee. We look forward to working with you to improve the health and safety of all Americans.

PREPARED STATEMENT OF THE NATIONAL RESPITE COALITION

Mr. Chairman, I am Jill Kagan, Chair of the ARCH National Respite Coalition, a network of respite providers, family caregivers, State and local agencies and organizations across the United States who support respite. Thirty State respite coalitions are also affiliated with the NRC. This statement is presented on behalf of the these organizations, as well as the members of the Lifespan Respite Task Force, a coalition of over 80 national and 100 State and local groups who supported the passage of the Lifespan Respite Care Act (Public Law 109-442). Together, we are requesting that the Subcommittee include funding for the Lifespan Respite Care Program administered by the U.S. Administration on Aging in the fiscal year 2011 Labor, HHS, and Education Appropriations bill at \$50 million. Given the serious fiscal constraints facing the Nation, this request has been reduced by one-half below the previous fiscal year's authorized and requested amount. This will enable:

- State replication of best practices in Lifespan Respite to allow all family caregivers, regardless of the care recipient's age or disability, to have access to affordable respite, and to be able to continue to play the significant role in long-term care that they are fulfilling today;
- Improvement in the quality of respite services currently available;
- Expansion of respite capacity to serve more families by building new and enhancing current respite options, including recruitment and training of respite workers and volunteers; and
- Greater consumer direction by providing family caregivers with training and information on how to find, use and pay for respite services.

Who Needs Respite?

In 2009, a national survey found that over 65 million family caregivers are providing care to individuals of any age with disabilities or chronic conditions (Caregiving in the U.S. 2009. Bethesda, MD: National Alliance for Caregiving (NAC) and Washington, DC: AARP, 2009). Family caregivers provide an estimated \$375 billion in uncompensated care, an amount almost as high as Medicare spending (\$432 billion in 2007) and more than total spending for Medicaid, including both Federal and State contributions and both medical and long-term care (\$311 billion in 2005) (Gibson and Hauser, 2008).

Family caregiving is not just an aging issue, but a lifespan one for the majority of the Nation's families. While the aging population is growing rapidly, the majority of family caregivers are caring for someone under age 75 (56 percent); 28 percent of family caregivers care for someone between the ages of 50–75, and 28 percent are caring for someone under age 50, including children (NAC and AARP, 2009). Many family caregivers are in the sandwich generation—46 percent of women who are caregivers of an aging family member and 40 percent of men also have children under the age of 18 at home (Aumann, Kerstin and Ellen Galinsky, et al. 2008). And 6.7 million children, are in the primary custody of an aging grandparent or other relative.

Families of the wounded warriors—those military personnel returning from Iraq and Afghanistan with traumatic brain injuries and other serious chronic and debilitating conditions—are at risk for limited access to respite. Even with enactment of the new VA Family Caregiver Support Program, the need for respite will remain high among all veterans and their family caregivers. Among family caregivers of

veterans whose illness, injury or condition is in some way related to military service surveyed in 2010, only 15 percent had received respite services from the VA or other community organization within the past 12 months. Caregivers whose veterans have PTSD are only about half as likely as other caregivers to have received respite services (11 percent vs. 20 percent) (NAC, *Caregivers Of Veterans—Serving On The Homefront*, November 2010). Sixty-eight percent of veterans' caregivers reported their situation as highly stressful compared to 31 percent of caregivers nationally who feel the same and three times as many say there is a high degree of physical strain (40 percent vs. 14 percent) (NAC, 2010). Veterans' caregivers specifically asked for up-to-date resource lists of respite providers in their local communities and help to find services—the very thing Lifespan Respite is charged to provide (NAC, 2010).

National, State and local surveys have shown respite to be the most frequently requested service of the Nation's family caregivers (Evercare and NAC, 2006). Other than financial assistance for caregiving through direct vouchers payments or tax credits, respite is the number one national policy related to service delivery that family caregivers prefer (NAC and AARP, 2009). Yet respite is unused, in short supply, inaccessible, or unaffordable to a majority of the Nation's family caregivers. The NAC 2009 survey found that despite the fact that among the most frequently reported unmet needs of family caregivers were “finding time for myself” (32 percent), “managing emotional and physical stress” (34 percent), and “balancing work and family responsibilities” (27 percent), nearly 90 percent of family caregivers across the lifespan are not receiving respite services at all.

Together, these family caregivers provide an estimated 80 percent of all long-term care in the United States. This percentage will only rise in the coming decades with an expected increase in the number of chronically ill veterans returning from war, greater life expectancies of individuals with Down's Syndrome and other disabling and chronic conditions, the aging of the baby boom generation, and the decline in the percentage of the frail elderly who are entering nursing homes.

Respite Barriers and the Effect on Family Caregivers

Barriers to accessing respite include reluctance to ask for help, fragmented and narrowly targeted services, cost, and the lack of information about how to find or choose a provider. Even when respite is an allowable funded service, a critically short supply of well-trained respite providers may prohibit a family from making use of a service they so desperately need. Lifespan Respite is designed to help States eliminate these barriers through improved coordination and capacity building.

While most families take great joy in helping their family members to live at home, however, it has been well documented that family caregivers experience physical and emotional problems directly related to their caregiving responsibilities. A majority of family caregivers (51 percent) caring for someone over the age of 18 have medium or high levels of burden of care, measured by the number of activities of daily living with which they provide assistance, and 31 percent of all family caregivers were identified as “highly stressed” (NAC and AARP, 2009). While family caregivers of children with special healthcare needs are younger than caregivers of adults, they give lower ratings to their health. Only 4 out of 10 consider their health to be excellent or very good (44 percent) compared to 6 in 10 (59 percent) caregivers of adults; 26 percent say their health is fair or poor, compared to 16 percent of those caring for adults. Caregivers of children are twice as likely as the general adult population to say they are in fair/poor health (26 percent vs 13 percent) (Provisional summary Health Statistics for US Adults, National Health Interview Survey, 2008, dated August 2009).

The decline of family caregiver health is one of the major risk factors for institutionalization of a care recipient, and there is evidence that care recipients whose caregivers lack effective coping styles or have problems with depression are at risk for falling, developing preventable secondary complications such as pressure sores and experiencing declines in functional abilities (Elliott & Pezent, 2008). Care recipients may also be at risk for encountering abuse from caregivers when the recipients have pronounced need for assistance and when caregivers have pronounced levels of depression, ill health, and distress (Beach et al., 2005; Williamson et al., 2001).

Supports that would ease their burden, most importantly respite, are too often out of reach or completely unavailable. Even the simple things we take for granted, like getting enough rest or going shopping, become rare and precious events. Restrictive eligibility criteria also preclude many families from receiving services or continuing to receive services for which they once were eligible. A mother of a 12-year-old with autism was denied respite by her State DD (Developmental Disability) agency because she was not a single mother, was not at poverty level, was not exhibiting any

emotional or physical conditions herself, and had only one child with a disability. As she told us, “Do I have to endure a failed marriage or serious health consequences for myself or my family before I can qualify for respite? Respite is supposed to be a preventive service.”

For the millions of families of children with disabilities, respite has been an actual lifesaver. However, for many of these families, their children will age out of the system when they turn 21 and they will lose many of the services, such as respite, that they currently receive. In fact, 46 percent of U.S. State units on aging identified respite as the greatest unmet need of older families caring for adults with lifelong disabilities.

Respite may not exist at all in some States for adult children with disabilities still living at home, or individuals under age 60 with conditions such as ALS, MS, spinal cord or traumatic brain injuries, or children with serious emotional conditions. In Tennessee, a young woman in her twenties gave up school, career and a relationship to move in and take care of her 53 year-old mom with MS when her dad left because of the strain of caregiving. Fortunately, she lives in Tennessee with a State Lifespan Respite Program. Now 31, she wrote, “And I was young—I still am—and I have the energy, but—it starts to weigh. Because we’ve been able to have respite care, it has made all the difference.”

Respite Benefits Families and is Cost Saving

Respite has been shown to be a most effective way to improve the health and well-being of family caregivers that in turn helps avoid or delay out-of-home placements, such as nursing homes or foster care, minimizes the precursors that can lead to abuse and neglect, and strengthens marriages and family stability. A U.S. Department of Health and Human Services report prepared by the Urban Institute found that higher caregiver stress among those caring for the aging increases the likelihood of nursing home entry. Reducing key stresses on caregivers, such as physical strain and financial hardship, through services such as respite would reduce nursing home entry (Spillman and Long, USDHHS, 2007). The budgetary benefits that accrue because of respite are just as compelling. Delaying a nursing home placement for just one individual with Alzheimer’s or other chronic condition for several months can save thousands of dollars. In an Iowa survey of parents of children with disabilities, a significant relationship was demonstrated between the severity of a child’s disability and their parents missing more work hours than other employees. It was also found that the lack of available respite appeared to interfere with parents accepting job opportunities. (Abelson, A.G., 1999)

Moreover, data from an ongoing research project of the Oklahoma State University on the effects of respite care found that the number of hospitalizations, as well as the number of medical care claims decreased as the number of respite care days increased (Fiscal Year 1998 Oklahoma Maternal and Child Health Block Grant Annual Report, July 1999). A Massachusetts social services program designed to provide cost-effective family centered respite care for children with complex medical needs found that for families participating for more than 1 year, the number of hospitalizations decreased by 75 percent, physician visits decreased by 64 percent, and antibiotics use decreased by 71 percent (Mausner, S., 1995).

In the private sector, the Metropolitan Life Insurance Company and the National Alliance for Caregivers found that U.S. businesses lose from \$17.1 billion to \$33.6 billion per year in lost productivity of family caregivers. (MetLife and National Alliance for Caregiving, 2006). A more recent study from the National Alliance on Caregiving and Evercare demonstrated that the economic downturn has had a particularly harsh effect on family caregivers. Of the 6 in 10 caregivers who are employed, 50 percent of them are less comfortable during the economic downturn with taking time off from work to care for a family member or friend. A similar percentage (51 percent) says the economic downturn has increased the amount of stress they feel about being able to care for their relative or friend. Respite for working family caregivers could help improve job performance and employers could potentially save billions.

Lifespan Respite Care Program Will Help

The Lifespan Respite Care Program is based on the success of statewide Lifespan Respite programs in Oregon, Nebraska, Wisconsin and Oklahoma. The Federal Lifespan Respite program is administered by the U.S. Administration on Aging, Department of Health and Human Services (HHS). AoA provides competitive grants to State agencies in concert with Aging and Disability Resource Centers working in collaboration with State respite coalitions or other State respite organizations. The program was authorized at \$53.3 million in fiscal year 2009 rising to \$95 million in fiscal year 2011. Congress appropriated \$2.5 million in fiscal year 2009 and again

in fiscal year 2010 and fiscal year 2011. Twenty-four States have received 3-year \$200,000 Lifespan Respite Grants from AoA since 2009. Another 9 or 10 States are expected to receive grants by August 2011.

The purpose of the law is to expand and enhance respite services, improve coordination, and improve respite access and quality. States are required to establish State and local coordinated Lifespan Respite care systems to serve families regardless of age or special need, provide new planned and emergency respite services, train and recruit respite workers and volunteers and assist caregivers in gaining access to services. Those eligible would include family members, foster parents or other adults providing unpaid care to adults who require care to meet basic needs or prevent injury and to children who require care beyond that required by children generally to meet basic needs.

Lifespan Respite, which is a coordinated system of community-based respite services, helps States use limited resources across age and disability groups more effectively, instead of each separate State agency or community-based organization being forced to reinvent the wheel or beg for small pots of money. Pools of providers can be recruited, trained and shared, administrative burdens can be reduced by coordinating resources, and savings used to fund new respite services for families who may not qualify for existing Federal or State programs. For the growing number of veterans returning home with TBI or other polytrauma, the shortage of staff qualified to provide respite to this population is especially critical. Lifespan Respite systems can make all the difference by ameliorating special barriers for this population. The Government Accountability Office summarized the innovative activities being taken by the 24 States to implement these State Lifespan Respite Systems in its report to Congress, *Respite Care: Grants and Cooperative Agreements Awarded to Implement the Lifespan Respite Care Act*. GAO-11-28R, October 22, 2010.

The Administration recommended \$10 million for Lifespan Respite in fiscal year 2012. This is a doubling of the Administration's previous request in fiscal year 2011 of \$5 million as part of their Middle Class Initiative. We are heartened to see that support for family caregiving is recognized as a critical component of a typical family's economic and social well-being and extremely grateful for the Administration's support. Still, we must not neglect that fact that 90 percent of the Nation's family caregivers are not receiving respite at all. More than half of them are caring for someone under age 75 with MS, ALS, traumatic brain or spinal cord injury, mental health conditions, developmental disabilities or cancer. \$10 million will not address the need for respite. Based on expenditures by State funded Lifespan Respite programs in the original best practice States, we estimate that an average sized State will need at least \$1 million to build a Lifespan Respite System that can better coordinate its services and funding streams, maximize use of existing resources, and leverage new dollars in both the public and private sectors to build respite capacity and serve the unserved.

No other Federal program mandates respite as its sole focus. No other Federal program would help ensure respite quality or choice, and no current Federal program allows funds for respite start-up, training or coordination or to address basic accessibility and affordability issues for families. We urge you to include \$50 million in the fiscal year 2012 Labor, HHS, Education appropriations bill so that Lifespan Respite Programs can be replicated in the States and more families, with access to respite, will be able to continue to play the significant role in long-term care that they are fulfilling today.

PREPARED STATEMENT OF THE NATIONAL RURAL HEALTH ASSOCIATION

The National Rural Health Association (NRHA) is pleased to provide the Labor, Health and Human Services, Education and Related Agencies Appropriations Subcommittee with a statement for the record on fiscal year 2012 funding levels for programs with a significant impact on the health of rural America.

The NRHA is a national nonprofit membership organization with more than 20,000 members that provides leadership on rural health issues. The Association's mission is to improve the health of rural Americans and to provide leadership on rural health issues through advocacy, communications, education and research. The NRHA membership consists of a diverse collection of individuals and organizations, all of whom share the common bond of an interest in rural health.

The NRHA is advocating for continued full funding for a group of rural health programs that assist many rural communities in maintaining and building a strong healthcare delivery system into the future. Most importantly, these programs help increase the capacity of the rural healthcare delivery system. Additional capacity that will be absolutely necessary with the addition of many newly insured Ameri-

cans under the Patient Protection and Affordable Care Act. These programs have been successful in increasing access to healthcare in rural areas, helping communities create new health programs for those in need and training the future health professionals that will give care to rural America. With modest investments, these programs are able to evaluate, study, and implement quality improvement programs and health information technology systems.

While recognizing the constraints of the current economic and budgetary climate, we would like to remind you of the critical importance of these rural health programs and request modest increases to ensure that these programs do not lose any ground. Even small investments in these “rural health safety net” programs go a long way and generate big returns in rural communities. Cuts to these programs do more harm than good and in the long run the Federal government will pay a much higher cost should these rural programs go away.

Some important rural health programs supported by the NRHA are outlined below.

Rural Health Outreach and Network Grants provide capital investment for planning and launching innovative projects in rural communities that later become self-sufficient. These grants are unique in the Federal system as they allow the community to choose what is most important for their own situation and then build a program around that. These grants have led to projects dealing with obesity and diabetes, information technology networks, oral screenings, preventive services, and many other health concerns. Due to the community nature of the grants and a focus on self-sustainability after the terms of the grant have run out—85 percent of the Outreach Grantees continue to deliver services even 5 full years after Federal funding had ended. Request: \$59.8 million

Rural Health Research and Policy forms the Federal infrastructure for rural health policy. Without these funds, rural America has no coordinated voice in the Department of Health and Human Services (HHS). In addition to the expertise provided to agencies such as the Centers for Medicare and Medicaid Services, this line item also funds rural health research centers across the country. These research centers provide the knowledge and the evidence needed for good policy making, both in the Federal Government and across the Nation. Additionally, we urge the Subcommittee to include in report language instructions to the Office of Rural Health Policy to direct additional funding to the State rural health associations. The State associations serve to coordinate rural health activities at the State level and have a strong record of positive outcomes. Request: \$10.76 million

State Offices of Rural Health are the State counterparts to the Federal rural health research and policy efforts, and form the State infrastructure for rural health policy. They assist States in strengthening rural healthcare delivery systems by maintaining a focal point for rural health within each State and by linking small rural communities with State and Federal resources to develop long term solutions to rural health problems. Without these funds, States would have diminished capacity to administer many of the rural health programs that are so critical to access to care. Request: \$10 million

Rural Hospital Flexibility Grants fund quality improvement and emergency medical service projects for Critical Access Hospitals across the country. This funding is essential. CAHs are by definition small hospitals with fewer than 25 beds; they do not have the size, volume or the expertise to do the types of quality improvement or information technology activities that they need to do. These grants allow statewide coordination and provide expertise to CAHs. Also funded in this line is the Small Hospital Improvement Program (SHIP), which provides grants to more than 1,500 small rural hospitals (50 beds or less) across the country to help improve their business operations, focus on quality improvement and to ensure compliance provisions related to health information privacy. Request: \$43.46 million

Rural and Community Access to Emergency Devices assists communities in purchasing emergency devices and training potential first responders in their use. Defibrillators double a victim's chance of survival after sudden cardiac arrest, which an estimated 163,221 Americans experience every year. Request: \$3.49 million

The Office for the Advancement of Telehealth supports distance-provided clinical services and is designed to reduce the isolation of rural providers, foster integrated delivery systems through network development and test a range of telehealth applications. Long-term, telehealth promises to improve the health of millions of Americans, provide constant education to isolated rural providers and save money through reduced office visits and expensive hospital care. These approaches are still new and unfolding and continued investment in the infrastructure and development is needed. Request: \$12.3 million

National Health Service Corps (NHSC) plays a critical role in providing primary healthcare services to rural underserved populations by placing healthcare providers

in our Nation's most underserved communities. Investment in our healthcare workforce is absolutely vital to support the newly insured population resulting from health reform. Programs like the NHSC help to maximize the capacity of our health system to care for patients. The Patient Protection and Affordable Care Act provided additional funding to the NHSC through the HHS Secretary's Community Health Center fund. The NRHA is supporting the President's request, which will ensure that the NHSC has access to the additional dedicated funding through the CHC Fund. Request: \$173.2 million

Title VII Health Professions Training Programs (with a significant rural focus):

- Rural Physician Pipeline Grants will help medical colleges to develop special rural training programs and recruit students from rural communities, who are more likely to return to their home regions to practice. Newly created under the Patient Protection and Affordable Care Act, this "grow-your-own" approach is one of the best and most cost-effective ways to ensure a robust rural workforce into the future. Request: \$
- Area Health Education and Centers (AHECs) financially support and encourage those training to become healthcare professionals to choose to practice in rural areas. Without this experience and support while in medical school, far fewer professionals would make the commitment to rural areas and facilities including Community Health Centers, Rural Health Clinics and rural hospitals. It has been estimated that nearly half of AHECs would shut down without Federal funding. The success of this program was recognized through increased authorized levels in the Patient Protection and Affordable Care Act. Request: \$75 million
- Geriatric Programs train health professionals in geriatrics, including funding for Geriatric Education Centers (GEC). There are currently 47 GECs nationwide that ensure access to appropriate and quality healthcare for seniors. Rural America has a disproportionate share of the elderly and could see a shortage of health providers without this program. Request: \$ 35.6 million

The NRHA appreciates the support throughout the fiscal year 2011 continuing resolution process and the opportunity to provide our recommendations for your fiscal year 2012 appropriations bill. Our request for continued funding for the rural health safety net is critical to maintaining access to high quality care in rural communities. We greatly appreciate the support of the Subcommittee and look forward to working with Members of Congress to continue making these important investments in rural health in fiscal year 2012 and into the future.

PREPARED STATEMENT OF THE NATIONAL SENIOR CORPS ASSOCIATION

Mr. Chairman, Members of the Committee, I testify today on behalf of the National Senior Corps Association, representing the interests and ideals of 500,000 senior volunteers and the directors, staff, and friends of local Foster Grandparent, Senior Companion, and RSVP programs throughout the country.

The recent agreement for fiscal year 2011 appropriations included a 20 percent cut in funding for RSVP—a devastating setback that threatens to deny 100,000 seniors the opportunity to serve their communities. We urge that this funding be restored, first and foremost, and that the Corporation for National and Community Service (CNCS) take particular care to do so in protecting opportunities for senior volunteers without interruption.

For fiscal year 2012, NSCA requests \$111,100,000 for the Foster Grandparent Program (FGP), \$63,000,000 for RSVP, and \$47,000,000 for the Senior Companion Program (SCP). This is an aggregate increase of \$200,000 over the fiscal year 2010 enacted level. In addition, we support an appropriation of \$5 million for demonstration projects to increase high school graduation rates through the Foster Grandparent Program and to support independent living for veterans through the Senior Companion Program.

SENIOR CORPS is a federally authorized and funded network of national service programs that provides older Americans with the opportunity to apply their life experiences to volunteer service. Senior Corps is comprised of the Foster Grandparent Program, RSVP, and the Senior Companion Program, through which Americans age 55 and older provide essential services to cost-effectively address critical community needs.

Foster Grandparent Program.—29,000 Foster Grandparents in 328 projects provide a cost-effective means to reach and support more than 280,000 at-risk children with special or exceptional needs annually who otherwise may not have the opportunity to receive individual assistance and attention from a caring adult. In 2009, Foster Grandparents volunteered 24.3 million hours.

- 81 percent of children served demonstrated improvements in academic performance. Mentored children have reduced truancy resulting in reduced school costs and, ultimately, reduced high school dropout rates and increased lifetime earnings.
- 90 percent demonstrated increased self-image. This includes improved health outcomes such as reductions in teen pregnancy and reduced or delayed use of tobacco, alcohol, or illicit drugs.
- 56 percent reported improved school attendance leading to increased graduation rates, increased post-secondary education, and higher lifetime earnings.
- 59 percent reported reduction in risky behavior, including reduced juvenile violence and property crimes, saving victim and court expenses, costly treatment of juvenile offenders, costs of adult crime, crime losses of victims and the societal costs of prosecuting and incarcerating adult offenders.
- In 2009, FGP volunteers mentored 41,767 children and youth, of which 5,400 were children of prisoners at high risk of repeating their parent's path.
- FGP intervention reduced need for social services, both short-term costs of counseling and long-term costs of public assistance.
- Based on conservative assumptions about outcomes and valuations, studies indicate a return benefit of \$2.72 for every dollar of resources used for mentoring programs. (Analyzing the Social Return on Investment in Youth Mentoring Programs, prepared by: Paul A. Anton, Wilder Research; and Prof. Judy Temple, University of Minnesota).

Foster Grandparent Program Profiles.—Foster Grandparent Birda Dillon completed the ninth grade, worked doing factory assembly for 25 years, raised 20+ children—14 of her own as well as grandchildren. She is a remarkable Foster Grandparent as the following remarks from her teacher in Benton Harbor, Michigan begin to illustrate: “Grandma is so good with these students. She knows just how to work with them to get them to read the words themselves. She is positive and knows how to get the students to sound the words out. George is reading so much better. I was surprised when he told me recently, ‘I need another book!’” I can’t spend one-on-one time with them, and she can. Birda is one of the best reading tutors I’ve encountered in my many years of teaching. She knows all of the tricks and tools to help the students help themselves. She said much of what she knows she has learned through her training as a Foster Grandparent. I appreciate her giftedness very much. We hope we can be together for a long, long time.” From Professional Volunteer who assists with site visits (a retired veteran teacher): “I complimented her on her teaching of reading and told her I was a reading teacher, too. I told her she was a natural! She said she hadn’t had any formal training; she wished she’d been a teacher, and I told her she was.” Three of the children Birda tutors have incarcerated parents.

Foster Grandparent Leila Williams: Leila serves in a first grade classroom at Washington Elementary School in Coloma, Michigan. “I had no idea how rewarding it would be. And I feel so much better. I love having a schedule, being busy, and I sleep so good at night. Thank you, for making my life better. I’m 91 years old, and getting younger.” Leila is matched with two children with parents in active military service. Leila’s teacher reports that as a result of Leila’s one-on-one attention, her two assigned students have developed positive relationships with Leila, improved socialization skills and have both improved reading skills, especially sight word recognition and fluency.

RSVP.—405,000 RSVP volunteers contributed 62 million hours of service in 2009 through 741 projects nationwide working with more than 65,000 community organizations. The average cost to support one RSVP volunteer is approximately \$145 a year, whereas the average annual value per volunteer is more than \$3,000. RSVP volunteers saved local communities \$1.25 billion in 2009.

- RSVP is continually strengthening its leadership role in engaging volunteers 55+ by providing nonprofit agencies with volunteers trained to recruit and coordinate other community members in support of the nonprofits mission and goals. In 2009, RSVP volunteers recruited 38,000 additional community volunteers.
- RSVP projects demonstrate that their volunteer services increase literacy scores for the 74,326 children they mentor—the National Education Association states the lowest hourly rate for teacher aides is \$10.31 reflecting a savings of \$16,858,623 in remedial reading assistance.
- 24,370 RSVP volunteers increased the capacity of the organizations where they serve by enhancing both the quality and quantity of services.
- In 2009, RSVP volunteers mentored 6,400 children of prisoners at high risk of repeating their parent’s path.

—RSVP volunteers provided 23,300 caregivers with respite services. A recent AARP survey of working caregivers reports that 30 percent of family caregivers either quit their jobs or reduce their work hours to take on more care giving responsibilities.

—RSVP volunteers supported 509,000 with Independent Living Services.

—30 percent of RSVP volunteers provided at least one service in the area of Health/Nutrition which includes in-home and congregate meals, food distribution/collection, immunization, etc. valued at more than \$27 million.

RSVP Program Profile.—The Beginning Alcohol and Addictions Basic Education Studies (BABES) program has been operating successfully for many years in districts throughout the Portage County, Wisconsin RSVP service area. Each year, hundreds of second graders in the various districts learn from their puppet friends (via the RSVP volunteers) about complex issues like peer pressure, good decision-making, and asking for help.

In 2009, over 600 second graders participated in the program. The intermediate outcome states that teachers in the second grade classes will observe children using phrases from the presentations and reminding others about the lessons they have learned. In 2009, the target was exceeded as 21 teachers returned surveys and 90 percent (19) reported they observed children using phrases from the BABES presentations. Teacher comments included: (1) “They have brought up coping, decision-making, peer pressure and self image when we are reading other stories. They have made a connection from these lessons to what is going on in their world.” (2) “One student came in from recess and said someone was peer pressuring her to do something on the playground. It was great hearing the term used!”

The end outcome states that students in second grade classes who complete the BABES program will show an increase in knowledge about alcohol and drug use and abuse and seeking help as measured on a pre/post test. In 2009, the target was exceeded as 74 percent (20 of 27 classes participating in BABES in 2009) of classes improved their scores on the post test by at least 10 percent.

While the program is successful because volunteers are willing to present the lessons, the coordination of the program is also an important piece. The RSVP Intergenerational Coordinator provides annual volunteer training, ensures volunteers have all the materials they need, works with the schools to schedule the program, ensures the pre and post tests are completed and returned and analyzes and reports the date collected to all the stakeholders.

Senior Companion Program.—15,200 Senior Companions serving in 194 projects provided 12.2 million hours of service helping 68,200 frail, homebound clients in need of assistance in order to remain living independently. Senior Companion Program services prevented premature and costly institutionalization at an annual savings well over \$200 million. The national average cost for 1 year in a nursing home is \$72,270; the assisted living facility yearly average cost is \$37,572. One Senior Companion volunteer assists 2–6 homebound clients for the annual investment of \$4,800.

—Senior Companions offered essential respite to nearly 9,000 primary caregivers who struggle to remain in the regular workforce while caring for their loved one.

—The Family Caregiver Alliance reports that families with long-term care responsibilities miss an average of 7.5 workdays each year.

—The MetLife Caregiving Cost Study of July 2006 reports the estimated cost to employers of full-time employed intense caregivers at a total of \$17.1 billion in lost productivity annually as well as absenteeism, workday interruptions, costs due to crisis in care, supervision costs associated with caregiver employees, costs with unpaid leave and reducing hours from full-time to part-time.

—Clients have significant, long-term mental health benefits and reduced rates of depression saving \$50–\$75 a month in medication.

—Cost of stress management therapy for one caregiver (\$125 per session) vs. respite provided by volunteer (4 hours of respite care = \$10.60 plus mileage average cost of \$3).

—Cost for a home health aide after a client’s release from the hospital is \$21 per hour as compared to \$2.65 per hour for a Senior Companion volunteer (at no cost to clients).

Senior Companion Program Profile.—Julia, an 80 year old woman who is blind was faced with having to leave her home in Rochester, NY due to her inability to see and complete the tasks of daily living needed to stay independent. While she had home health aide service to help her bathe, dress and clean her apartment, her family wasn’t able to be with her during the day and evening due to their work schedules and their own family commitments.

Julia was given two Senior Companion (SC) volunteers. One came each day mid-morning after the home health aide left and stayed until early afternoon. The SC kept Julia company, escorted her to the bathroom when needed, fixed lunch and ensured she was okay daily. The second SC came about 5 p.m. each evening. She fixed dinner, visited, cleaned up after dinner and helped Julia get ready and into bed each evening.

Between these two volunteers Julia was able to stay living at home an additional 5+ years. At an average cost of \$70,000 annually for long term care compared to the cost of her SC services at approximately \$4,800 annually per companion, a savings of over \$300,000 was saved.

It has been stated that baby boomer and senior volunteers represent our Nation's single and fastest growing resource. During this unprecedented economic crisis facing our Nation, the number of baby boomer and senior volunteers should be greatly expanded and mobilized as solutions to the problems facing our local communities. NSCA's 2012 budget request will provide the opportunity for thousands more older adults to serve in their communities and enhance the lives of those most in need, including children with special needs, the frail and isolated elderly striving to maintain independence, and expanding the services of local non-profit agencies.

The 2010 national value of one hour of volunteer service was estimated at \$21.36. Senior Corps volunteers' 98.2 million service hours in 2010 = \$2.1 billion savings.

PREPARED STATEMENT OF THE NATIONAL TECHNICAL INSTITUTE FOR THE DEAF

Mr. Chairman and Members of the Committee: I am pleased to present the fiscal year 2012 budget request for NTID, one of eight colleges of RIT, in Rochester, New York. Created by Congress by Public Law 89-36 in 1965, we provide university technical and professional education for students who are deaf and hard-of-hearing, leading to successful careers in high-demand fields for a sub-population of individuals historically facing high rates of unemployment and under-employment. We also provide baccalaureate and graduate level education for hearing students in professions serving deaf and hard-of-hearing individuals. As of fall 2010, NTID served a total of 1,521 students from across the Nation, including 1,263 deaf and hard-of-hearing undergraduate students and 147 hearing undergraduate students. NTID students live, study and socialize with more than 15,000 hearing students on the RIT campus.

NTID has fulfilled its mission with distinction for 43 years.

Budget Request

As shown below, NTID's fiscal year 2012 budget request was \$64,677,000 in Operations and \$2,000,000 in Construction, as part of a plan that would provide NTID with a total of \$10,000,000 in Construction over the next 5 years to fund needed capital projects. The NTID request is a total of \$66,677,000; the President's request is \$63,037,000 in Operations and \$2,000,000 in Construction, for a total of \$65,037,000.

FISCAL YEAR 2012 BUDGET REQUEST STATUS

	Operations	Construction	Total
NTID Request	\$64,677,000	\$2,000,000	\$66,677,000
President's Request ¹	63,037,000	2,000,000	65,037,000
Difference	1,640,000	1,640,000

¹ For fiscal years 2009, 2010 and most likely, 2011, NTID's Operations budget has been funded at \$63,037,000; the President's recommended Operations budget for fiscal year 2012 would mark four consecutive years of funding at the same amount.

For the past 3 years, NTID has been able to absorb the same level of funding in Operations primarily due to two factors: (1) a self-initiated budget-reduction/revenue enhancement campaign from fiscal year 2003 through fiscal year 2007; and (2) limited RIT-mandated salary increases in recent years. However, realized savings from the campaign now have been reallocated and are no longer available. Furthermore, the limited increases from fiscal year 2009 through fiscal year 2011 mean that NTID has fallen significantly behind its salary benchmarks. RIT has mandated a 3 percent salary increase for all faculty and staff in the coming fiscal year.

While NTID certainly would benefit from a budget increase to support upcoming strategic initiatives (see below), we understand the resource challenges facing the Committee this year. While an additional \$1,640,000 beyond the President's recommended Operations funding for fiscal year 2012 is needed, we are amenable to

meeting this need by shifting funds designated in the President's 2012 budget from Construction to Operations. This would ensure NTID stays within the total allocation proposed in the President's 2012 budget of \$65,037,000, and will allow us to better meet our Operations needs. In the meantime, we will continue to seek non-Federal funding to support immediate construction/renovation needs while continuing to communicate about critical long-term construction needs.

Enrollment

In fiscal year 2011 (fall 2010), we attracted the largest enrollment in our 43-year history. Truly a national program, NTID has enrolled students from all 50 States. Our current enrollment is 1,521. Over the last 5 years our enrollment has increased 22 percent (271 students). For fiscal year 2012, NTID anticipates maintaining this record high enrollment level. Our enrollment history over the last 5 years is shown below:

NTID ENROLLMENTS: FIVE-YEAR HISTORY

Fiscal Year	Deaf/Hard-of-Hearing Students			Hearing Students			Grand Total
	Undergrad	Grad RIT	MSSE	Subtotal	Interpreting Program	MSSE	Subtotal
2007	1,017	47	31	1,095	130	25	155
2008	1,103	51	31	1,185	130	28	158
2009	1,212	48	24	1,284	135	31	166
2010	1,237	38	32	1,307	138	29	167
2011	1,263	40	29	1,332	147	42	189
							1,521

Student Accomplishments

For our graduates, over the past 5 years, an average of 93 percent have been placed in jobs commensurate with the level of their education (using the Bureau of Labor Statistics methodology). Of our fiscal year 2009 graduates (the most recent class for which numbers are available), 59 percent were employed in business and industry, 21 percent in education/nonprofits, and 20 percent in Government.

Graduation from NTID has a demonstrably positive effect on students' earnings over a lifetime, and results in a noteworthy reduction in dependence on Supplemental Security Income (SSI), Social Security Disability Insurance (SSDI) and public assistance programs. In fiscal year 2007, NTID, the Social Security Administration, and Cornell University examined approximately 13,000 deaf and hard-of-hearing individuals who applied and attended NTID over our entire history. We learned that graduating from NTID has significant economic benefits. By age 50, deaf and hard-of-hearing baccalaureate graduates earned on average \$6,021 more per year than those with associate degrees, who in turn earned \$3,996 more per year on average than those who withdrew before graduation. Students who withdrew earned \$4,329 more than those not admitted. Students who withdrew experienced twice the rate of unemployment as graduates.

The same studies showed 78 percent of these individuals were receiving SSI benefits at age 19, but when they were 50 years old, only 1 percent of graduates drew these benefits, while on average 19 percent of individuals who withdrew or were not admitted continued to participate in the SSI program. Graduates also accessed SSDI, an unemployment benefit, at far lesser rates than students who withdrew; by age 50, 34 percent of non-graduates were receiving SSDI, while 22 percent of baccalaureate graduates and 27 percent of associate graduates were receiving them. Considering the reduced dependency on these Federal income support programs, the Federal investment in NTID returns significant societal dividends.

NTID clearly makes a significant, positive difference in earnings, and in lives.

Strategic Initiatives Beginning Fiscal Year 2011

In 2010, NTID completed Strategic Decisions 2020, a strategic plan based on our founding mission statement. This statement sets forth our institutional responsibility to work with students to develop their academic, career and life-long learning skills as future contributors in a rapidly changing world. It also recognizes our role as a special resource for preparing individuals who are deaf and hard-of-hearing, for conducting applied research in areas critical to the advancement of individuals who are deaf and hard-of-hearing, and for disseminating our collective and cumulative expertise.

Strategic Decisions 2020 establishes key initiatives responding to future challenges and shaping future opportunities. These initiatives, which began implementation in fiscal year 2011, include:

- Pursuing enrollment targets and admissions and programming strategies that will result in increasing numbers of our graduates achieving baccalaureate degrees and higher, while maintaining focus and commitment to quality associate-level degree programs leading directly to the workplace;
- Improving services to under-prepared students through working with regional partners to implement intensive summer academic preparation programs in selected high-growth, ethnically diverse areas of the country. Through this initiative, NTID will identify those students demonstrating promise for success in career-focused degree-level programs and beyond, and provide consultation to others regarding postsecondary educational alternatives;
- Expanding NTID's role as a National Resource Center of Excellence regarding the education of deaf and hard-of-hearing students in senior high school (grades 10, 11 and 12) and at the postsecondary level. Components of this role as a National Resource Center of Excellence will include:
 - Center for Excellence in STEM Education.*—NTID currently is working to develop an externally funded Center of Excellence on STEM Education for Deaf and Hard-of-Hearing Students. This is an example of making our expertise available nationally and enhancing deaf and hard-of-hearing students' access to STEM fields.
 - NTID Research Centers.*—NTID will organize research resources into Research Centers focused on the following strategic areas of research: Teaching and Learning; Communication; Technology, Access, and Support Services; and Employment and Adaptability to Social Changes and the Global Workplace.
 - Outreach Programs.*—Extending outreach activities to junior and senior high school students who are deaf and hard-of-hearing, many of who represent AALANA populations, to expand their horizons regarding a college education. We also support other colleges and universities serving students who are deaf

and hard-of-hearing, as well as post-college adults who are deaf and hard-of-hearing.

—Enhancing efforts to become a recognized national leader in the exploration, adaptation, testing, and implementation of new technologies to enhance access to, and support of, learning by deaf and hard-of-hearing individuals.

NTID Academic Programs

NTID offers high quality, career-focused associate degree programs preparing students for specific well-paying technical careers. NTID also is expanding the number of its transfer associate degree programs, currently numbering seven, to better serve the higher achieving segment of our student population seeking bachelor's and master's degrees in an increasingly demanding marketplace. These transfer programs provide seamless transition to baccalaureate studies in the other colleges of RIT. In support of those deaf and hard-of-hearing students enrolled in the other RIT colleges, NTID provides a range of access services (including interpreting, real-time speech-to-text captioning, and note-taking) as well as tutoring services. One of NTID's greatest strengths is our outstanding track record of assisting high-potential students to gain admission to, and graduate from, the other colleges of RIT at rates comparable to their hearing peers.

A cooperative education (co-op) component is an integral part of academic programming at NTID and prepares students for success in the job market. A co-op gives students the opportunity to experience a real-life job situation and focus their career choice. Students develop technical skills and enhance vital personal skills such as teamwork and communication, which will make them better candidates for full-time employment after graduation. Over 250 students each year participate in 10-week co-op experiences that augment their academic studies, refine their social skills, and prepare them for the competitive working world.

Summary

It is extremely important that our funding be provided at the full level requested by the President as we continue our mission to prepare deaf and hard-of-hearing people to enter the workplace and society. We ask only that the funds provided by the President for Construction be moved into Operations.

Our alumni have demonstrated that they can achieve independence, contribute to society, and find sustainable employment as a result of NTID. Research shows that NTID graduates over their lifetimes are employed at much higher rates, earn substantially more (therefore paying significantly more in taxes), and participate at a much lower rate in SSI, SSDI, and public assistance programs than those who withdraw or who apply but do not attend NTID.

We are hopeful that the members of the Committee will agree that NTID, with its long history of successful stewardship of Federal funds and outstanding educational record of service with people who are deaf and hard-of-hearing, remains deserving of your support and confidence.

FISCAL YEAR 2012 NTID BUDGET REQUEST

FISCAL YEAR 2012 NTID BUDGET STATUS

	Operations	Construction	Total
NTID fiscal year 2011 funding	\$65,437,000	\$240,000	\$65,677,000
NTID original request	64,677,000	2,000,000	66,677,000
NTID updated request ¹	65,437,000	1,240,000	66,677,000

¹ Note: Our updated request keeps within the limits of our original request; however, it moves money from our Construction request to maintain our Operations funding at the 2011 level.

Context

Enrollment is the highest in NTID history with 1,521 students, a 22 percent increase over the past 5 years.

In an effort to maximize non-Federal revenues, NTID increased tuition by 5 percent for fiscal year 2012. From fiscal year 2006-fiscal year 2012, student tuition has increased by 40 percent.

Support for NTID is an investment with significant returns in the form of increased employment and reduced dependence on Federal SSI and SSDI payments for our students. NTID's employment rate in 2010 was 89 percent in spite of a challenging job market and averages to be 93 percent over the past 5 years.

Prior to fiscal year 2011, NTID had received \$63,037,000 in Operations for 2009 and 2010 and was slated to receive that sum again in 2011. NTID was able to accommodate level funding in the past through a combination of additional non-Fed-

eral revenues and targeted fiscal control strategies with minimal impact on services and programs for students. However, the \$65,437,000 that NTID received in Operations for fiscal year 2011 was crucial in order to offset record student enrollment and use of access services, prevent enrollment caps, and avoid the elimination of outreach programs, equipment purchases, and matching endowments.

NTID's updated budget request for fiscal year 2012 maintains Operations funding at the fiscal year 2011 level, to support our increased enrollment, increased provision of services, and upcoming strategic initiatives. It contains \$1,240,000 requested for Construction to begin major renovations to a building designed 30 years ago that houses 3 major NTID programs.

Possible actions if less than fiscal year 2011 operations funding received

Limit admission of new students for Fall 2012.—NTID has never limited the number of qualified students who can enroll—to do so would mean denying deaf and hard-of-hearing students the opportunity to receive a state-of-the-art technical education with the unparalleled access services found at NTID.

Hiring freeze and possible staff furloughs.—83 percent of NTID's resources support salaries/wages—NTID would have to reduce expenditures with a hiring freeze and possible furlough of staff, leaving positions vacant while serving more students than ever before.

Substantial reduction or elimination of summer outreach programs.—This would affect deaf and hard-of-hearing pre-college youth, especially young women and African-American and Latino-American youth, by eliminating programs that encourage them to continue on to college, especially in the STEM fields.

Substantial reduction or elimination of equipment purchases.—NTID's mission is to prepare deaf and hard-of-hearing students for technical and professional careers in fields characterized by cutting-edge technologies. Without the most technologically updated equipment available, the education of our students will be impaired significantly.

Substantial reduction or elimination of matching endowment funds.—NTID would be unable to fulfill its commitment to match endowment donations to the Institute, decreasing the level of scholarship support for students.

PREPARED STATEMENT OF NEMOURS

Nemours thanks Chairman Harkin, Ranking Member Shelby and members of the Subcommittee for the opportunity to submit written testimony on the fiscal year 2012 Labor, Health and Human Services, Education and Related Agencies Appropriations bill. Nemours, one of the Nation's leading child health systems, is dedicated to improving children's health and well-being by offering a spectrum of clinical treatment, research, advocacy, educational health, and prevention services extending to families in the communities it serves.

About Nemours

Nemours has developed a model of care that integrates clinical preventive and treatment services for children with population-based prevention initiatives. No other health system in the Nation has made the same level of investment in community-based prevention programs, policies and practices to reach all children in the community, not just those who cross our doors. Nemours Health and Prevention Services (NHPS) has developed a comprehensive, multi-sector obesity prevention initiative to reach all children in Delaware. To achieve the greatest impact, NHPS considers the many places where children and families spend their time: schools, child care, healthcare settings, community centers and neighborhoods. The goal is to reinforce consistent messages through policy and practice changes in each setting to help children make healthy food and lifestyle choices and to stay physically active.

In school settings, NHPS works with district-level teams of administrators, teachers, counselors, school nurses, parents and students to encourage wellness policies and provide training and educational tools that support policy and environmental changes to encourage healthier eating and more physical activity on school campuses. In the child care setting, Nemours worked with government leaders to help Delaware become a frontrunner for policies that support healthy eating and physical activity. NHPS provides training and educational tools to help child care providers promote healthy behaviors for young children.

In the primary care setting, Nemours convened pediatric primary care providers from across the State to participate in a learning collaborative focused on improving office-based weight management and health promotion skills. Practitioners learned about new interventions and received tools for use in the office setting, as well as take-home materials for families. In the community, NHPS works with youth-serv-

ing organizations to promote healthy eating and physical activity and to develop champions who will model the behavior and help spread the message. We also work to create an environment that promotes healthy lifestyles.

Community-based Prevention

As an integrated health system that is very engaged with the community, Nemours sees first-hand the impact of chronic disease on our Nation's children. We treat obese young children at our clinics, and we know that unhealthy habits that contribute to obesity are starting at a very young age. In fact, nationally, over 24 percent of children ages 2–5 are already overweight or obese. Much of what influences their health is outside the realm of the healthcare system, which is why we have made and will continue to make significant investments in community-based prevention. We believe that investing in clinical and community-based prevention is an important way to ensure that children grow up to be healthy adults. We are supportive of the Prevention and Public Health Fund and urge the Committee to utilize the resources provided from this Fund to support the integration of clinical and community-based prevention and to evaluate the outcomes associated with those investments. In particular, we are supportive of Community Transformation Grants.

Community Transformation Grants draw upon the best of what we know works: strong coalitions, multi-sector, public-private partnerships, evidence-based approaches, and evaluation. In Delaware, Nemours has successfully used this combination of approaches to stem the rising childhood obesity curve between 2006 and 2008. These grants allow us to build upon this foundation and spread what works to other communities. The purpose of the grants is to support the implementation, evaluation, and dissemination of evidence-based community preventive health activities in order to reduce chronic disease rates, prevent the development of secondary conditions, address health disparities, and develop a stronger evidence-base of effective prevention programming. In short, these grants would help us in our efforts to help children grow up healthy. If we are serious about the commitment to improving health, then we need to transform the places where children live, learn and play, which is exactly what these grants are designed to accomplish. We urge the Committee to provide \$221.06 million for Community Transformation Grants in fiscal year 2012, which is the level requested by the President.

Children's Hospital Graduate Medical Education

Another important priority for Nemours is the healthcare workforce, particularly the pediatric workforce. Children's hospitals care for large numbers of children with complex health conditions. In order to achieve high quality clinical care and outcomes, these specialty hospitals need to have well-trained residents and physicians. The Children's Hospital Graduate Medical Education program (CHGME) provides support for graduate medical education to freestanding children's hospitals that train resident physicians. The CHGME program was created to correct an unintended inequity in the GME financing system, which is tied to the number of Medicare beneficiaries being treated at a hospital. Freestanding children's hospitals generally do not provide care to Medicare-eligible patients, and were therefore largely left out of the GME financing system. The CHGME program has addressed this issue.

CHGME supports 55 freestanding children's hospitals that train approximately 40 percent of all pediatricians, 43 percent of all pediatric specialists, and many pediatric researchers and physicians who require pediatric training. In 2009, CHGME supported the training of 5,439 pediatric resident physicians. This is a very important contribution to training our pediatric workforce, which continues to experience shortages, particularly in pediatric specialty care. A 2009 survey by the National Association of Children's Hospitals and Related Institutions (NACHRI) found that national shortages contribute to vacancies in children's hospitals that commonly last 12 months or longer for a number of pediatric specialties. These vacancies often result in longer wait times for children to see pediatric specialists.

At the Alfred I. duPont Hospital for Children, over 300 residents are trained each year. Under the supervision of physicians, these residents provide care for inpatients and also provide primary and specialty care in outpatient settings, including clinics. In 2010, CHGME covered approximately 54 percent of the cost of the Nemours residency program.

Unfortunately, the President's budget proposes to eliminate funding for this critical program. We urge Congress to reject this short-sighted cut and to continue to provide support for training the next generation of pediatricians, pediatric specialists and pediatric researchers. Nemours urges the Subcommittee to provide \$317.5

million for CHGME in fiscal year 2012, the same amount that was provided in fiscal year 2010.

Conclusion

Nemours appreciates the opportunity to submit written testimony. As an integrated child health system, we have prioritized investments in clinical and community-based prevention and our workforce because we believe that in the long-run these investments will bend the health curve and the cost curve. We recognize that the Nation's fiscal situation requires a close examination of the programs and priorities that the Federal Government funds. As you make these critical funding decisions, we hope that prevention and the healthcare workforce will remain priorities of the Subcommittee in fiscal year 2012.

PREPARED STATEMENT OF THE NEPHCURE FOUNDATION

Nephrotic syndrome (NS) is a collection of signs and symptoms caused by diseases that attack the kidney's filtering system. These diseases include focal segmental glomerulosclerosis (FSGS), Minimal Change Disease (MCD) and Membranous Nephropathy (MN). When affected, the kidney filters leak protein from the blood into the urine and often cause kidney failure which requires dialysis or kidney transplantation. According to a Harvard University report, 73,000 people in the United States have lost their kidneys as a result of FSGS. Unfortunately, the causes of FSGS and other filter diseases are very poorly understood.

FSGS is the second leading cause of NS and is especially difficult to treat. There is no known cure for FSGS and current treatments are difficult for patients to endure. These treatments include the use of steroids and other dangerous substances which lower the immune system and contribute to severe bacterial infections, high blood pressure and other problems in patients, particularly child patients. In addition, children with NS often experience growth retardation and heart disease. Finally, NS caused by FSGS, MCD or MN is idiopathic and can often reoccur, even after a kidney transplant.

FSGS disproportionately affects minority populations and is five times more prevalent in the African American community. In a groundbreaking study funded by NIH, researchers found that FSGS is associated with two APOL1 gene variants. These variants are common in African Americans but not in European Americans, and it is thought that these variants developed as an evolutionary response to African sleeping sickness.

FSGS also has a large social impact on the United States. FSGS leads to end-stage renal disease (ESRD) which is one of the most costly chronic diseases to manage. In 2007, the Medicare program alone spent \$24 billion, 6 percent of its entire budget, on ESRD. In 2005, FSGS accounted for 12 percent of ESRD cases in the United States, at an annual cost of \$3 billion. It is estimated that there are currently approximately 20,000 Americans living with ESRD due to FSGS.

Research on FSGS could achieve tremendous savings in Federal healthcare costs and reduce health status disparities—both critical and appropriate themes of the current administration. For this reason, and on behalf of the thousands of families that are significantly affected by this disease, we recommend the following:

- \$35 billion for the National Institutes of Health (NIH) and a corresponding increase to the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK).
- Continue to support the Nephrotic Syndrome Rare Disease Clinical Research Network at the Office of Rare Diseases Research (ORDR).
- Support continued expansion of the FSGS/NS research portfolio at NIDDK and the National Institute on Minority Health and Health Disparities (NIMHD) by funding more research proposals for glomerular disease.
- Support awareness activities through the Centers for Disease Control and Prevention Chronic Kidney Disease Program.

Encourage FSGS/NS Research at NIH

There is no known cause or cure for FSGS and scientists tell us that much more research needs to be done on the basic science behind FSGS/NS. More research could lead to fewer patients undergoing ESRD and tremendous savings in healthcare costs in the United States.

With collaboration from other Institutes and Centers, ORDR established the Rare Disease Clinical Research Network. This network provided an opportunity for the NephCure Foundation, the University of Michigan, and other university research health centers to come together to form the Nephrotic Syndrome Study Network (NEPTUNE). NEPTUNE is a relatively new collaboration and has tremendous po-

tential to make significant advancements in NS and FSGS research because it pools resources and develops a database of NS patients who are interested in participating in clinical trials. The addition of Federal resources, as well as NIH coordination of this important initiative, is crucial to ensuring the best possible outcomes for RDCRN and NEPTUNE.

The NephCure Foundation is also grateful to the NIDDK for issuing a program announcement (PA) that serves to initiate grant proposals on glomerular disease. This PA was issued in March of 2007 and utilizes the R01 mechanism to award funding to glomerular disease researchers. In February, 2010 the PA was re-released and is now scheduled to expire in 2013. We ask the subcommittee to encourage NIDDK to continue to issue glomerular disease PAs.

Due to the disproportionate burden of FSGS on minority populations, the NephCure Foundation feels that it is appropriate for NIMHD to develop an interest in this research. However, NIMHD has not supported any research on FSGS. We ask the Subcommittee to encourage ORDR, NIDDK, and NIMHD to collaborate on research that studies the incidence and cause of this disease among minority populations. We also ask the Subcommittee to urge NIDDK and the NIMHD undertake culturally appropriate efforts aimed at educating minority populations about glomerular disease.

Raise Glomerular Disease Awareness at CDC

When glomerular disease strikes, the resulting NS causes a loss of protein in the urine and edema. The edema often manifests itself as puffy eyelids, a symptom that many parents and physicians mistake as allergies. With experts projecting a substantial increase in nephrotic syndrome in the coming years, there is a clear need to educate pediatricians and family physicians about glomerular disease and its symptoms.

It would be of great benefit for CDC to begin raising public awareness of the glomerular diseases in an attempt to diagnose patients earlier.

We ask the Subcommittee to encourage CDC to establish a glomerular disease education and awareness program aimed at both the general public and healthcare providers.

PREPARED STATEMENT OF NEUROFIBROMATOSIS, INC.

Thank you for the opportunity to submit testimony to the Subcommittee on the importance of continued funding at the National Institutes of Health (NIH) for Neurofibromatosis (NF), a terrible genetic disorder closely linked to many common diseases widespread among the American population.

On behalf of Neurofibromatosis, Inc., a national coalition of NF advocacy groups, I speak on behalf of the 100,000 Americans who suffer from NF as well as approximately 175 million Americans who suffer from diseases and conditions linked to NF such as cancer, brain tumors, heart disease, memory loss and learning disabilities. Thanks in large measure to this Subcommittee's strong and enduring support, scientists have made enormous progress since the discovery of the NF1 gene in 1990 resulting in clinical trials now being undertaken at NIH with broad implications for the general population.

What is Neurofibromatosis (NF)?

NF is a genetic disorder involving the uncontrolled growth of tumors along the nervous system which can result in terrible disfigurement, deformity, deafness, blindness, brain tumors, cancer, and even death. NF can also cause other abnormalities such as unsightly benign tumors across the entire body and bone deformities. In addition, approximately one-half of children with NF suffer from learning disabilities. While not all NF patients suffer from the most severe symptoms, all NF patients and their families live with the uncertainty of not knowing whether they will be seriously affected because NF is a highly variable and progressive disease.

NF is not rare. It is the most common neurological disorder caused by a single gene and three times more common than Muscular Dystrophy and Cystic Fibrosis combined, but it is not widely known because it has been poorly diagnosed for many years. Approximately 100,000 Americans have NF, and it appears in approximately 1 in every 2,500 births. It strikes worldwide, without regard to gender, race or ethnicity. Approximately 50 percent of new NF cases result from a spontaneous mutation in an individual's genes and 50 percent are inherited. There are three types of NF: NF1, which is more common, NF2, which primarily involves tumors causing deafness and balance problems, and schwannomatosis, the hallmark of which is severe pain. In addition, advances in NF research stand to benefit over 175 million

Americans in this generation alone because NF is directly linked to many of the most common diseases affecting the general population.

When a child is diagnosed with NF it means tumors can grow anytime, anywhere on his/her nervous system, from the day he/she is born until the day he/she dies with no way to predict when or how severely the tumors will affect his/her body—and no viable way to treat the disease outside of surgery—which often results in more tumors that grow twice as fast. That same child then has a 50 percent chance to pass the gene to his/her children. That is an overwhelming diagnosis and it bears repeating: NF is one of the most common genetic disorders in our country and has no cure and no viable treatment. But that is changing. The immediate future holds real promise.

Link to Other Illnesses

Researchers have determined that NF is closely linked to cancer, heart disease, learning disabilities, memory loss, brain tumors, and other disorders including deafness, blindness and orthopedic disorders, primarily because NF regulates important pathways common to these disorders such as the RAS, cAMP and PAK pathways. Research on NF therefore stands to benefit millions of Americans:

Cancer.—NF is closely linked to many of the most common forms of human cancer, affecting approximately 65 million Americans. In fact, NF shares these pathways with 70 percent of human cancers. Research has demonstrated that NF's tumor suppressor protein, neurofibromin, inhibits RAS, one of the major malignancy causing growth proteins involved in 30 percent of all cancer. Accordingly, advances in NF research may well lead to treatments and cures not only for NF patients, but for all those who suffer from cancer and tumor-related disorders. Similar studies have also linked epidermal growth factor receptor (EGF-R) to malignant peripheral nerve sheath tumors (MPNSTs), a form of cancer which disproportionately strikes NF patients.

Heart disease.—Researchers have demonstrated that mice completely lacking in NF1 have congenital heart disease that involves the endocardial cushions which form in the valves of the heart. This is because the same ras involved in cancer also causes heart valves to close. Neurofibromin, the protein produced by a normal NF1 gene, suppresses ras, thus opening up the heart valve. Promising new research has also connected NF1 to cells lining the blood vessels of the heart, with implications for other vascular disorders including hypertension, which affects approximately 50 million Americans. Researchers believe that further understanding of how an NF1 deficiency leads to heart disease may help to unravel molecular pathways involved in genetic and environmental causes of heart disease.

Learning disabilities.—Learning disabilities are the most common neurological complication in children with NF1. Research aimed at rescuing learning deficits in children with NF could open the door to treatments affecting 35 million Americans and 5 percent of the world's population who also suffer from learning disabilities. In NF1 the neurocognitive disabilities range includes behavior, memory and planning. Recent research has shown there are clear molecular links between autism spectrum disorder and NF1; as well as with many other cognitive disabilities. Tremendous research advances have recently led to the first clinical trials of drugs in children with NF1 learning disabilities. These trials are showing promise. In addition because of the connection with other types of cognitive disorders such as autism, researchers and clinicians are actively collaborating on research and clinical studies, pooling knowledge and resources. It is anticipated that what we learn from these studies could have an enormous impact on the significant American population living with learning difficulties and could potentially save Federal, State, and local governments, as well as school districts, billions of dollars annually in special education costs resulting from a treatment for learning disabilities.

Memory loss.—Researchers have also determined that NF is closely linked to memory loss and are now investigating conducting clinical trials with drugs that may not only cure NF's cognitive disorders but also result in treating memory loss as well with enormous implications for patients who suffer from Alzheimer's disease and other dementias.

Deafness.—NF2 accounts for approximately 5 percent of genetic forms of deafness. It is also related to other types of tumors, including schwannomas and meningiomas, as well as being a major cause of balance problems.

Scientific Advances

Thanks in large measure to this Subcommittee's support; scientists have made enormous progress since the discovery of the NF1 gene in 1990. Major advances in just the past few years have ushered in an exciting era of clinical and translational research in NF with broad implications for the general population.

These recent advances have included:

- Phase II and Phase III clinical trials involving new drug therapies for both cancer and cognitive disorders;
- Creation of a National Clinical and Pre-Clinical Trials Infrastructure and NF Centers;
- Successfully eliminating tumors in NF1 and NF2 mice with the same drug;
- Developing advanced mouse models showing human symptoms;
- Rescuing learning deficits and eliminating tumors in mice with the same drug;
- Determining the biochemical, molecular function of the NF genes and gene products; and
- Connecting NF to more and more diseases because of NF's impact on many body functions.

Congressional support for NF research

The enormous promise of NF research, and its potential to benefit over 175 million Americans who suffer from diseases and conditions linked to NF, has gained increased recognition from Congress and the NIH. This is evidenced by the fact that 12 institutes at NIH are currently supporting NF research (NCI, NHLBI, NINDS, NIDCD, NHGRI, NCRR, NIMH, NIGMS, NEI, NIA, NICHD, and OD), and NIH's total NF research portfolio has increased from \$3 million in fiscal year 1990 to an estimated \$24 million in fiscal year 2011. Given the potential offered by NF research for progress against a range of diseases, we are hopeful that NIH will continue to build on the successes of this program by funding this promising research and thereby continuing the enormous return on the taxpayers' investment.

We respectfully request that you include the following report language on NF research at the National Institutes of Health within your fiscal year 2012 Labor, Health and Human Services, Education Appropriations bill.

Neurofibromatosis [NF].—NF is an important research area for multiple NIH Institutes; therefore the Committee supports efforts to increase funding and resources toward NF research and treatment. As NF is connected to many forms of cancer in children and adults; the Committee encourages the NCI to substantially increase its NF research portfolio in pre-clinical and clinical trials by applying newly developed and existing drugs. The Committee also encourages the NCI to support NF centers, clinical trials consortia, patient databases, and biospecimen repositories. The Committee also urges additional focus from the NHLBI, given NF's involvement with hypertension and congenital heart disease. Because NF causes tumors to grow on the nerves throughout the body, the Committee urges the NINDS to continue aggressive research on nerve damage and repair which has strong implications not only for NF but for spinal cord and brain injury, learning disabilities and attention deficit disorders. In addition, the Committee continues to encourage the NICHD and NIMH to expand funding of clinical trials for NF patients in the area of learning disabilities. Children with NF1 are prone to the development of severe bone deformities, including scoliosis; the Committee encourages NIAMS to expand its NF1 research portfolio. NF2 accounts for approximately 5 percent of genetic forms of deafness; the Committee therefore encourages the NIDCD to expand its NF2 research portfolio. The Committee encourages NEI to expand its NF research portfolio to advance the cause of treating Optic gliomas, vision loss and cataracts, major clinical problems associated with NF. The Committee encourages the NHGRI to expand its NF portfolio given that NF represents an ideal model to study the genomics of cancer predisposition, learning and behavior, and bone disease translatable to personalized medicine for affected individuals.

We appreciate the Subcommittee's strong support for NF research and will continue to work with you to ensure that opportunities for major advances in NF research are aggressively pursued. Thank you.

PREPARED STATEMENT OF THE NURSING COMMUNITY

The Nursing Community is a forum for professional nursing organizations to collaborate on a wide spectrum of healthcare and nursing issues, including practice, education, and research. These 56 organizations are committed to promoting America's health through nursing care. Collectively, the Nursing Community represents over 850,000 Registered Nurses (RNs), Advanced Practice Registered Nurses (APRNs—including certified nurse-midwives, nurse practitioners, clinical nurse specialists, and certified registered nurse anesthetists), nurse executives, nursing students, nursing faculty, and nurse researchers. Together, our organizations work collaboratively to increase funding for the Nursing Workforce Development programs (authorized under Title VIII of the Public Health Service Act [42 U.S.C. 296 et

seq.), the National Institute of Nursing Research (NINR), and to secure authorized funding for Nurse-Managed Health Clinics so that American nurses have the support needed to provide high quality healthcare to the Nation.

Nurses are involved in every aspect of healthcare, and if the nursing workforce is not strengthened, the healthcare system will continue to suffer. Currently, RNs comprise the largest group of health professionals with approximately 3.1 million licensed providers. Nurses offer essential care to patients as well as our Nation's active duty military and veterans in a variety of settings, including hospitals, ambulatory care clinics, long-term care facilities, community or public health areas, schools, workplaces, and private homes. In addition, many nurses pursue graduate degrees to assume roles as advanced practice registered nurses who practice autonomously; become nurse faculty, nurse researchers, nurse administrators, and advanced public health nurses. Nurses also specialize in areas such as mental and women's health, pain management, hospice and palliative care, nephrology, oncology, rehabilitation, forensics, dermatology, urology, and care coordination. They are critical team members in all departments such as intensive and critical care, pediatrics, geriatrics, medical surgical, and operating rooms. RNs and APRNs hold a holistic view of health.

With the Patient Protection and Affordable Care Act [Public Law 111-148] (ACA) focus on creating a system that will increase access to quality care, emphasize prevention, and decrease cost, it is critical that a substantial investment be made in our RN and APRN workforce, in the scientific research that provides the basis for nursing practice, and in the safety-net facilities they operate.

In an article published in the July/August 2009 issue of Health Affairs, Dr. Peter Buerhaus, a noted health professions workforce analyst, and colleagues confirmed that although the economic recession has led to a temporary easing of the nursing shortage in some parts of the country, the overall shortfall in the number of nurses needed is expected to grow to 260,000 by the year 2025. Three major factors contribute to this growing demand for nursing care. First, over 275,000 practicing RNs are over the age of 60 according to the 2008 National Sample Survey of Registered Nurses. When the economy rebounds, many of these nurses will seek retirement. Second, America's population is aging. Older Americans will seek more healthcare services creating an influx of consumers and necessitate the need for quality nursing care. Finally, the ACA will expand the number of individuals seeking care by 32 million.

Furthermore, in a report released by the Institute of Medicine and Robert Wood Johnson Foundation titled, *The Future of the Nursing: Leading Change, Advancing Health*, clear and evidence based guidance was provided on how to shape nursing's role in healthcare delivery as the system undergoes considerable changes. The report's key messages include:

- Nurses should practice to the full extent of their education and training; scope of practice limitations should be removed.
- Nurses should achieve higher levels of education and training through an improved education system that promotes seamless academic progression.
- Nurses should be full partners with other healthcare professionals in redesigning healthcare in the United States.
- Effective workforce planning and policymaking require better data collection and an improved information infrastructure.

To achieve these goals, different levels of support will be needed for all nurses and each of the funding requests outlined below will help to meet not only the goals of the IOM report, but the larger national goals of access to high quality, cost effective care.

ADDRESSING THE DEMAND: NURSING WORKFORCE DEVELOPMENT PROGRAMS

The Nursing Workforce Development programs, authorized under Title VIII of the Public Health Service Act (42 U.S.C. 296 et seq.), helped build the supply and distribution of qualified nurses to meet our Nation's healthcare needs since 1964. Over the last 47 years, these programs addressed all aspects of supporting the workforce—education, practice, retention, and recruitment. The Title VIII programs bolster nursing education at all levels, from entry-level preparation through graduate study, and provide support for institutions that educate nurses for practice in rural and medically underserved communities. Today, the Title VIII programs are essential to ensure the demand for nursing care is met. Between fiscal year 2006 and 2009, the Title VIII programs supported over 347,000 nurses and nursing students as well as numerous academic nursing institutions, and healthcare facilities.

Results from the American Association of Colleges of Nursing's (AACN) 2010–2011 Title VIII Student Recipient Survey included responses from 1,459 students

who noted that these programs played a critical role in funding their nursing education. The survey showed that 80 percent of the students receiving Title VIII funding are attending school full-time. By supporting full-time students, the Title VIII programs are helping to ensure that students enter the workforce without delay. The programs also address the current demand for primary care providers. Nearly one-third of respondents reported that their career goal is to become a nurse practitioner. Approximately 80 percent of nurse practitioners provide primary care services throughout the United States. Additionally, the respondents identified working in rural and underserved areas as future goals, with becoming a nurse faculty member, a nurse practitioner, or a certified registered nurse anesthetist as the top three nursing positions for their career aspirations.

The Nursing Community respectfully requests \$313.075 million for the Nursing Workforce Development programs authorized under Title VIII of the Public Health Service Act in fiscal year 2012 as recommended in the President's fiscal year 2012 budget proposal.

BUILDING THE SCIENCE: THE NATIONAL INSTITUTE OF NURSING RESEARCH

As one of the 27 Institutes and Centers at the National Institutes of Health (NIH), the NINR funds research that establishes the scientific basis for quality patient care. Nurse researchers make significant advances in and contributions to health prevention and care. In addition, they work collaboratively as well as part of multidisciplinary research teams with colleagues from other fields and are vital in setting the national research agenda.

The Nursing Community respectfully requests \$163 million for the National Institute of Nursing Research in fiscal year 2012. Nursing research is an essential part of scientific endeavors to improve the Nation's health. Knowledge of care across the lifespan is critical to the present and future health of the Nation. Research funded at the NINR helps to integrate biology and behavior as well as design new technology and tools. At a time when healthcare needs are changing, nursing care must be firmly grounded in nursing science. The four strategic areas of emphasis for research at NINR are promoting health and preventing disease, eliminating health disparities, improving quality of life, and setting directions for end-of-life research.

The science advanced at NINR is integral to the future of the Nation's healthcare system. Through grants, research training, and interdisciplinary collaborations, NINR addresses care management of patients during illness and recovery, reduction of risks for disease and disability, promotion of healthy lifestyles, enhancement of quality of life for those with chronic illness, and care for individuals at the end of life. NINR's research fosters advances in nursing practice, improves patient care, and attracts new students to the profession.

SUPPORTING SAFETY NET FACILITIES: NURSE-MANAGED HEALTH CLINICS

The ACA amended Sec. 330 of the Public Health Service Act to provide grant eligibility to Nurse-Managed Health Clinics (NMHCs) to support operating costs and authorized up to \$50 million a year for this purpose. NMHCs are defined as a nurse-practice arrangement, managed by APRNs, that provides primary care or wellness services to underserved or vulnerable populations and that is associated with a school, college, university or department of nursing, federally qualified health center, or independent nonprofit health or social services agency. Nurse-Managed Health Clinics successfully engage communities and address critical health needs for underserved populations.

The Nursing Community respectfully requests \$20 million for the Nurse-Managed Health Clinics authorized under Title III of the Public Health Service Act in fiscal year 2012 as recommended in the President's fiscal year 2012 budget proposal.

NMHCs provide care to clients and patients in clinics located in places like public housing, on blighted urban streets, on Native American reservations, in rural communities, in senior citizen centers, in elementary schools, in storefronts, and even in churches. The services these clinics provide include primary care, health promotion, and disease prevention. Furthermore, NMHCs also act as important teaching and practice sites for nursing students.

The care provided in these sites directly contributes to positive health outcomes and savings in the long term. In one U.S. city alone, nurses at an NMHC see their patients almost twice as frequently as other providers, and their patients are hospitalized 30 percent less and use the emergency room 15 percent less often than those of other healthcare providers. Providing funding for these centers is a direct investment in the specific health needs of localized communities.

Without a workforce of well-educated nurses providing evidence-based care to those who need it most, including our growing aging population, the healthcare sys-

tem is not sustainable. The Nursing Community's request of \$313.075 million in fiscal year 2012 for the Title VIII Nursing Workforce Development programs, \$163 million for the NINR, and \$20 million for NMHCs will help ensure access to quality care provided by America's nursing workforce.

MEMBERS OF THE NURSING COMMUNITY SUBMITTING THIS TESTIMONY

Academy of Medical-Surgical Nurses	Association of Women's Health, Obstetric and Neonatal Nurses
American Academy of Ambulatory Care Nursing	Commissioned Officers Association
American Academy of Nurse Practitioners	Dermatology Nurses' Association
American Academy of Nursing	Gerontological Advanced Practice Nurses Association
American Assembly for Men in Nursing	Hospice and Palliative Nurses Association
American Association of Colleges of Nursing	Infusion Nurses Society
American Association of Critical-Care Nurses	International Association of Forensic Nurses
American Association of Nurse Anesthetists	International Nurses Society on Addictions
American Association of Nurse Assessment Coordinators	International Society of Psychiatric Nurses
American College of Nurse Practitioners	National Association of Clinical Nurse Specialists
American College of Nurse-Midwives	National Association of Nurse Practitioners in Women's Health
American Holistic Nurses Association	National Association of Pediatric Nurse Practitioners
American Nephrology Nurses' Association	National Black Nurses Association
American Nurses Association	National Coalition of Ethnic Minority Nurse Associations
American Organization of Nurse Executives	National Nursing Centers Consortium
American Psychiatric Nurses Association	National Organization of Nurse Practitioner Faculties
American Society for Pain Management Nursing	Nurses Organization of Veterans Affairs
American Society of PeriAnesthesia Nurses	Oncology Nursing Society
Association of Community Health Nursing Educators	Public Health Nursing Section, American Public Health Association
Association of periOperative Registered Nurses	Society of Urologic Nurses and Associates
Association of Rehabilitation Nurses	
Association of State and Territorial Directors of Nursing	

PREPARED STATEMENT OF THE ONCOLOGY NURSING SOCIETY

OVERVIEW

The Oncology Nursing Society (ONS) appreciates the opportunity to submit written comments for the record regarding fiscal year 2012 funding for cancer and nursing related programs. ONS, the largest professional oncology group in the United States, composed of more than 35,000 nurses and other health professionals, exists to promote excellence in oncology nursing and the provision of quality care to those individuals affected by cancer. As part of its mission, the Society honors and maintains nursing's historical and essential commitment to advocacy for the public good.

In 2010, an estimated 1.529 million Americans were diagnosed with cancer, and more than 569,490 lost their battle to this terrible disease; at the same time the national nursing shortage is expected to worsen. Overall, age is the number one risk factor for developing cancer. Approximately 77 percent of all cancers are diagnosed at age 55 and older.¹ Despite these grim statistics, significant gains in the war against cancer have been made through our Nation's investment in cancer research and its application. Research holds the key to improved cancer prevention, early detection, diagnosis, and treatment, but such breakthroughs are meaningless, unless we can deliver them to all Americans in need. Moreover, a recent survey of ONS members found that the nursing shortage is having an impact in oncology physician

¹American Cancer Society. *Cancer Facts and Figures 2010*. <http://www.cancer.org/Research/CancerFactsFigures/CancerFactsFigures/cancer-facts-and-figures-2010>.

offices and hospital outpatient departments. Some respondents indicated that when a nurse leaves their practice, they are unable to hire a replacement due to the shortage—leaving them short-staffed and posing scheduling challenges for the practice and the patients. These vacancies in all care settings create significant barriers to ensuring access to quality care.

To ensure that all people with cancer have access to the comprehensive, quality care they need and deserve, ONS advocates ongoing and significant Federal funding for cancer research and application, as well as funding for programs that help ensure an adequate oncology nursing workforce to care for people with cancer. ONS stands ready to work with policymakers at the local, State, and Federal levels to advance policies and programs that will reduce and prevent suffering from cancer and sustain and strengthen the Nation's nursing workforce. We thank the Subcommittee for its consideration of our fiscal year 2012 funding request detailed below.

SECURING AND MAINTAINING AN ADEQUATE ONCOLOGY NURSING WORKFORCE

Oncology nurses are on the front lines in the provision of quality cancer care for individuals with cancer—administering chemotherapy, managing patient therapies and side-effects, working with insurance companies to ensure that patients receive the appropriate treatment, providing treatment education and counseling to patients and family members, and engaging in myriad other activities on behalf of people with cancer and their families. Cancer is a complex, multifaceted chronic disease, and people with cancer require specialty-nursing interventions at every step of the cancer experience. People with cancer are best served by nurses specialized in oncology care, who are certified in that specialty.

As the overall number of nurses is expected to decline in the coming years, we likely will experience a commensurate decrease in the number of nurses trained in the specialty of oncology. With an increasing number of people with cancer needing high-quality healthcare, coupled with an inadequate nursing workforce, our Nation could quickly face a cancer care crisis of serious proportion, with limited access to quality cancer care, particularly in traditionally underserved areas. A study in the *New England Journal of Medicine* found that nursing shortages in hospitals are associated with a higher risk of complications—such as urinary tract infections and pneumonia, longer hospital stays, and even patient death.² Without an adequate supply of nurses, there will not be enough qualified oncology nurses to provide the quality cancer care to a growing population of people in need, and patient health and well-being could suffer.

Of additional concern is that our Nation also will face a shortage of nurses available and able to conduct cancer research and clinical trials. With a shortage of cancer research nurses, progress against cancer will take longer because of scarce human resources coupled with the reality that some practices and cancer centers' resources could be funneled away from cancer research to pay for the hiring and retention of oncology nurses to provide direct patient care. Without a sufficient supply of trained, educated, and experienced oncology nurses, we are concerned that our Nation may falter in its delivery and application of the benefits from our Federal investment in research.

ONS joins our colleagues from all nursing sectors and specialties to request \$313.075 million for the Health Resources and Services Administrations (HRSA) Title VIII programs in fiscal year 2012, as recommended in the President's fiscal year 2012 budget. With additional funding in fiscal year 2012, the HRSA Workforce Development Programs will have much-needed resources to address the multiple factors contributing to the nationwide nursing shortage. Advanced nursing education programs play an integral role in supporting registered nurses interested in advancing in their practice and becoming faculty. As such, these programs must be adequately funded in the coming year.

ONS strongly urges Congress to provide HRSA with this amount to ensure that the agency has the resources necessary to fund a higher rate of nursing scholarships and loan repayment applications and support other essential endeavors to sustain and boost our Nation's nursing workforce. Nurses—along with patients, family members, hospitals, and others—have joined together in calling upon Congress to provide this essential level of funding. The National Coalition for Cancer Research (NCCR), a nonprofit organization comprised of 23 national cancer organizations, and One Voice Against Cancer (OVAC), a collaboration of 39 national nonprofit organiza-

²Needleman J., Buerhaus P., Mattke S., Stewart M., Zelevinsky K. "Nurse-Staffing Levels and the Quality of Care in Hospitals." *New England Journal of Medicine* 346:, (May 30, 2002): 1715–1722.

tions, are also advocating \$313.075 million in fiscal year 2012 for the Nurse Reinvestment Act. ONS and its allies have serious concerns that without full funding, the Nurse Reinvestment Act will prove an empty promise, and the current and expected nursing shortage will worsen, and people will not have access to the quality care they need and deserve.

SUSTAIN AND SEIZE CANCER RESEARCH OPPORTUNITIES

Our Nation has benefited immensely from past Federal investment in biomedical research at the National Institutes of Health (NIH). ONS has joined with the broader health community in advocating a \$35 billion for NIH in fiscal year 2012. This level of investment will allow NIH to sustain and build on its research progress, while avoiding the severe disruption to advancement that could result from a minimal increase. Cancer research is producing amazing breakthroughs—leading to new therapies that translate into longer survival and improved quality of life for cancer patients. In recent years, we have seen extraordinary advances in cancer research, resulting from our national investment, which have produced effective prevention, early detection, and treatment methods for many cancers. To that end, ONS calls upon Congress to allocate \$5.740 billion to the National Cancer Institute (NCI), as well as \$231 million to the National Center for Minority Health and Health Disparities in fiscal year 2012 to support the battle against cancer.

The National Institute of Nursing Research (NINR) supports basic and clinical research to establish a scientific basis for the care of individuals across the life span—from management of patients during illness and recovery, to the reduction of risks for disease and disability and the promotion of healthy lifestyles. These efforts are crucial in translating scientific advances into cost-effective healthcare that does not compromise quality of care for patients. Additionally, NINR fosters collaborations with many other disciplines in areas of mutual interest, such as long-term care for older people, the special needs of women across the life span, bioethical issues associated with genetic testing and counseling, and the impact of environmental influences on risk factors for chronic illnesses, such as cancer. ONS joins with others in the nursing community and NCCR in advocating a fiscal year 2012 allocation of \$163 million for NINR.

BOOST OUR NATION'S INVESTMENT IN CANCER PREVENTION, EARLY DETECTION, AND AWARENESS

Approximately two-thirds of cancer cases are preventable through lifestyle and behavioral factors and improved practice of cancer screening. Although the potential for reducing the human, economic, and social costs of cancer by focusing on prevention and early detection efforts remains great, our Nation does not invest sufficiently in these strategies. The Nation must make significant and unprecedented Federal investments today to address the burden of cancer and other chronic diseases, and to reduce the demand on the healthcare system and diminish suffering in our Nation, both for today and tomorrow.

As the Nation's leading prevention agency, the Centers for Disease Control and Prevention (CDC) plays an important role in translating and delivering, at the community level, what is learned from research. Therefore, ONS joins with our partners in the cancer community in calling on Congress to provide additional resources for the CDC to support and expand much-needed and proven effective cancer prevention, early detection, and risk reduction efforts. Specifically, ONS advocates the following fiscal year 2012 funding levels for the following CDC programs:

- \$275 million for the National Breast and Cervical Cancer Early Detection Program;
- \$65 million for the National Cancer Registries Program;
- \$70 million for the Colorectal Cancer Prevention and Control Initiative;
- \$50 million for the Comprehensive Cancer Control Initiative;
- \$25 million for the Prostate Cancer Control Initiative;
- \$5 million for the National Skin Cancer Prevention Education Program;
- \$10 million for the Gynecologic Cancer and Education and Awareness (Johanna's Law);
- \$10 million for the Ovarian Cancer Control Initiative; and
- \$6 million for the Geraldine Ferraro Blood Cancer Program.

CONCLUSION

ONS maintains a strong commitment to working with Members of Congress, other nursing and oncology groups, patient organizations, and other stakeholders to ensure that the oncology nurses of today continue to practice tomorrow, and that we recruit and retain new oncology nurses to meet the unfortunate growing demand

that we will face in the coming years. By providing the fiscal year 2012 funding levels detailed above, we believe the Subcommittee will be taking the steps necessary to ensure that our nation has a sufficient nursing workforce to care for the patients of today and tomorrow and that our nation continues to make gains in our fight against cancer.

PREPARED STATEMENT OF THE OVARIAN CANCER NATIONAL ALLIANCE

The Ovarian Cancer National Alliance (the Alliance) appreciates the opportunity to submit comments for the record regarding the Alliance's fiscal year 2012 funding recommendations. We believe these recommendations are critical to ensure advances to help reduce and prevent suffering from ovarian cancer.

For 14 years, the Alliance has worked to increase awareness of ovarian cancer and advocate for additional Federal resources to support research that would lead to more effective diagnostics and treatments. As an umbrella organization with approximately 50 national, State and local organizations, the Alliance unites the efforts of survivors, grassroots activists, women's health advocates and healthcare professionals to bring national attention to ovarian cancer. The Ovarian Cancer National Alliance is the foremost advocate for women with ovarian cancer in the United States. To advance the interests of women with ovarian cancer, the organization advocates at a national level for increases in research funding for the development of an early detection test, improved healthcare practices and life-saving treatment protocols. The Ovarian Cancer National Alliance educates healthcare professionals and raises public awareness of the risks, signs and symptoms of ovarian cancer.

According to the American Cancer Society, in 2010, more than 22,000 American women were diagnosed with ovarian cancer and approximately 15,000 lost their lives to this terrible disease. Ovarian cancer is the fifth leading cause of cancer death in women. Currently, more than half of the women diagnosed with ovarian cancer will die within 5 years. While ovarian cancer has symptoms, there is no reliable early detection test. Most women are diagnosed in Stage III or Stage IV, when survival rates are low. If diagnosed early, more than 90 percent of women will survive for 5 years, but when diagnosed later, less than 30 percent will.

Only a few treatments have been approved by the Food and Drug Administration (FDA) for ovarian cancer treatment. These are platinum-based therapies and women needing further rounds of treatment are frequently resistant to them. More than 70 percent of ovarian cancer patients will have a recurrence at some point, underlying the need for treatments to which patients do not grow resistant.

For all of these reasons, we urgently call on Congress to appropriate funds to find solutions.

As part of this effort, the Alliance advocates for continued Federal investment in the Centers for Disease Control and Prevention's (CDC) Ovarian Cancer Control Initiative. The Alliance respectfully requests that Congress provide \$10 million for the program in fiscal year 2012.

The Alliance also fully supports Congress in taking action on educating Americans about ovarian cancer through providing funding for The Gynecologic Cancer Education and Awareness Act (Johanna's Law) [Public Law 111-324]. The Alliance respectfully requests that Congress provide \$10 million to implement The Gynecologic Cancer Education and Awareness Act (Johanna's Law) in fiscal year 2012.

Further, the Alliance urges Congress to continue funding the Specialized Programs of Research Excellence (SPORes), including the five ovarian cancer sites. These programs are administered through the National Cancer Institute (NCI) of the National Institutes of Health (NIH). The Alliance respectfully requests that Congress provide \$5.74 billion to the National Cancer Institute for fiscal year 2012.

CENTERS FOR DISEASE CONTROL AND PREVENTION

THE OVARIAN CANCER CONTROL INITIATIVE

As the statistics indicate, late detection and, therefore, poor survival are among the most urgent challenges we face in the ovarian cancer field. The CDC's cancer program, with its strong capacity in epidemiology and excellent track record in public and professional education, is well positioned to address these problems. As the Nation's leading prevention agency, the CDC plays an important role in translating and delivering at the community level what is learned from research, especially ensuring that those populations disproportionately affected by cancer receive the benefits of our Nation's investment in medical research.

Congress established the Ovarian Cancer Control Initiative at the CDC in November 1999 with bipartisan, bicameral support. Congress' directive to the agency was to develop an appropriate public health response to ovarian cancer and conduct several public health activities targeted toward reducing ovarian cancer morbidity and mortality.

The CDC's Ovarian Cancer Control Initiative conducts research about early detection, treatment and survivorship nationwide to increase understanding of ovarian cancer. Some of the Ovarian Cancer Control Initiative's notable studies include: a study of women who died of ovarian cancer within three managed care organizations to investigate end-of-life care; the Ovarian Cancer Treatment Patterns and Outcomes study, which attempted to determine how the stage of cancer, the specialty of a surgeon and the success of the surgery contributed to the survival of ovarian cancer patients diagnosed between 1997 and 2000; and a study to examine geographic access to subspecialists for treating ovarian cancer.

THE GYNECOLOGIC CANCER EDUCATION AND AWARENESS ACT (JOHANNA'S LAW)

It is critical for women and their healthcare providers to be aware of the signs, symptoms and risk factors of ovarian and other gynecologic cancers. Often, women and providers mistakenly confuse ovarian cancer signs and symptoms with those of gastrointestinal disorders or early menopause. While symptoms may seem vague—bloating, pelvic or abdominal pain, increased abdominal size and bloating and difficulty, eating or feeling full quickly, or urinary symptoms (urgency or frequency)—the underlying disease can be deadly without proper medical intervention.

In recognition of the need for awareness and education, Congress unanimously passed Johanna's Law in 2006, enacted in early 2007. This law provides for an education and awareness campaign that will increase providers' and women's awareness of all gynecologic cancers including ovarian. Johanna's Law was reauthorized in 2010.

Thanks to funding under Johanna's Law, more women are learning how to identify the signs and symptoms of gynecologic. From September 2010 to January 2011, the broadcast PSAs have been played 68,630 times, generating 154,632,815 audience impressions (the number of times they have been seen or heard), worth \$7,491,846 in donated placements. Additionally, since October 2010:

- there have been 25,706 plays of the TV PSAs, worth \$2,800,805 in donated airtime,
- there have been 9,701 plays of English TV spots,
- there have been 16,005 plays of Spanish TV spots,
- the PSAs have aired in the top markets, including Los Angeles, Chicago, Philadelphia, San Francisco, Boston, Dallas/Fort Worth, Atlanta, Tampa/St. Petersburg, Pittsburgh, PA, Salt Lake City, Raleigh/Durham, Green Bay, Baltimore, Tucson, Cleveland, Phoenix, Tulsa, Orlando, Hartford/New Haven, Houston, Spokane, and Seattle/Tacoma, among others, and
- English spots have aired during popular programs such *Today*, *Good Morning America*, *CBS Morning News*, *Access Hollywood*, *Cold Case*, *Real Housewives of Orange County*, *The Bachelor*, *The View*, *Dr. Oz Show*, *Ellen DeGeneres Show*, *The Doctors*, *Entertainment Tonight*, and *Late Night with David Letterman* during the hours of 8 a.m. to midnight.

With continued funding, the CDC will be able to continue to print and distribute brochures, maintain and update the web resources, develop additional educational materials such as posters for physician offices, complete continuing education materials for healthcare providers, and reach out to women beyond the original 40–60 year-old initial target group.

CDC CHRONIC DISEASE PROGRAM CONSOLIDATION

The President's budget proposal for fiscal year 2012 recommends consolidating all of the Centers for Disease Control and Prevention's (CDC) chronic disease programs that are focused on heart disease and stroke, diabetes, cancer, arthritis, nutrition, and other health-related issues into one competitive grant program. It is our understanding that the Gynecologic Cancer Education and Awareness Act (Johanna's Law) and the Ovarian Cancer Control Initiative would be included in this all-encompassing competitive grant program. These programs, with congressional support, have been able to increase understanding and raise awareness of ovarian and other women's cancers that afflict Americans.

While we support efforts to improve the efficiency of Federal programs, we oppose shifting control and funding of these programs away from Congress. Moreover, given that ovarian cancer mortality rates have remained virtually unchanged for decades and currently there is no early detection test for the disease, we feel strongly that

the CDC should maintain dedicated efforts focused on reducing ovarian cancer mortality and morbidity. As such, we recommend that Johanna's Law and the Ovarian Cancer Control Initiative remain standalone line items in the fiscal year 2012 Labor, Health and Human Services, and Education (LHHS) appropriations bill.

NATIONAL CANCER INSTITUTE

The National Cancer Institute is the chief funder of ovarian cancer research in the United States and the world. In 2009, the National Cancer Institute funded over 170 studies solely dedicated to bettering our scientific understanding of ovarian cancer. These studies investigated diverse topics such as the effect of Vitamin D on ovarian cancer prevention and treatment, whether Prolactin is a risk biomarker of ovarian cancer, and whether viruses can be converted into ovarian cancer-fighting agents. Research investigators who receive funding from the National Cancer Institute study cancer are located all across the United States. According to Families USA, every dollar in Federal research spending generates about \$2 in economic activity in local economies where funded projects are located.

SPECIALIZED PROGRAMS OF RESEARCH EXCELLENCE IN THE NATIONAL INSTITUTES OF HEALTH

The Specialized Programs of Research Excellence were created by the NCI in 1992 to support translational, organ site-focused cancer research. The ovarian cancer SPORes began in 1999. There are five currently funded Ovarian Cancer SPORes located at the MD Anderson Cancer Center, the Fred Hutchinson Cancer Research Center, the Fox Chase Cancer Center, the Dana Farber/Harvard Cancer Center and the Mayo Clinic Cancer Center.

These SPORes programs have made outstanding strides in understanding ovarian cancer, as illustrated by their more than 300 publications as well as other notable achievements, including the development of an infrastructure between Ovarian SPORes institutions to facilitate collaborative studies on understanding, early detection and treatment of ovarian cancer.

CLINICAL TRIALS

The National Cancer Institute supports clinical research—the only way to test the safety and efficacy of potential new treatments for ovarian cancer. An example of NCI-funded clinical research is a new 5-year study addressing the lack of knowledge about causes and risk factors for ovarian cancer in African American women conducted by University Hospitals Case Medical Center and Case Western Reserve University School of Medicine. Another study funded by the National Cancer Institute compared the efficacy and safety of a dose-dense regimen of single-agent cisplatin with a standard 3-weekly schedule in first-line chemotherapy for advanced epithelial ovarian cancer. The study found that increasing dose intensity of cisplatin does not improve PFS or OS compared with standard chemotherapy.

NCI supports the Gynecology Oncology Group, a more than 50-member collaborative focusing on cancers of the female reproductive system. From 2008 until present, the GOG has published 103 articles about ovarian cancer. An important and recent finding from the GOG, the GOG 218 study, was that women with advanced cancer who received chemotherapy followed by maintenance use of Avastin increased survival time without their disease worsening compared to chemotherapy alone.

SUMMARY

The Alliance maintains a long-standing commitment to work with Congress, the administration, and other policy makers and stakeholders to improve the survival rate for women with ovarian cancer through education, public policy, research and communication. Please know we appreciate and understand that our Nation faces many challenges and Congress has limited resources to allocate; however, we are concerned that without increased funding to bolster and expand ovarian cancer education, awareness and research efforts, the nation will continue to see growing numbers of women losing their battle with this terrible disease.

On behalf of the entire ovarian cancer community—patients, family members, clinicians and researchers—we thank you for your leadership and support of Federal programs that seek to reduce and prevent suffering from ovarian cancer. We request your support for our appropriations requests for fiscal year 2012 that include \$10 million for the CDC's Ovarian Cancer Control Initiative, \$10 million for The Gynecologic Cancer Education and Awareness Act (Johanna's Law) and \$5.74 billion to NCI.

PREPARED STATEMENT OF THE PANCREATIC CANCER ACTION NETWORK

Mr. Chairman and members of the Subcommittee: My name is Julie Fleshman and I am submitting this testimony on behalf of the Pancreatic Cancer Action Network.

Founded in 1999, the Pancreatic Cancer Action Network is a nationwide network of individuals dedicated to advancing research, supporting patients and fostering hope for the families and loved ones affected by this disease.

Pancreatic cancer continues to be one of the deadliest cancers in this country. In fact, it is the only cancer tracked by both the American Cancer Society and the National Cancer Institute (NCI) that still has a 5-year survival rate in the single digits. This is even more astounding because the overall 5-year survival rate for all cancers was 50 percent in the 1970s and is now 68 percent. Last year, pancreatic cancer struck more than 43,000 Americans and resulted in 36,800 deaths. The similarity of these statistics underscores its deadliness: indeed, most patients die within months of their diagnosis.

There is no question that we have made important progress in many forms of cancer. There is also no question that this progress has been lacking in pancreatic cancer. The fact remains that there are still no early detection tools or effective treatments. A patient diagnosed today generally hears the same words as a patient diagnosed 40 years ago, "I'm sorry, but there is not much that we can do for you. Go home and get your affairs in order." The Pancreatic Cancer Action Network believes that the time has come for bold action and has launched a new mission to double the 5-year survival rate by 2020. This is an ambitious but achievable goal.

Dismal as the picture is today, unless something is done soon, it will only get worse. A recently published study in the *Journal of Clinical Oncology* predicts that the number of new pancreatic cancer cases will increase by 55 percent over the next two decades.

Why has there been so little change in the mortality rate associated with pancreatic—and what can be done about it?

Progress has been slow in large part because the Federal Government's investment in pancreatic cancer research has been weak. The Pancreatic Cancer Action Network recently published a report, "Pancreatic Cancer: A trickle of Federal funding for a river of need", analyzing the investment made by the NCI into this disease. The analysis shows that pancreatic cancer is behind in nearly every important grant category funded by the Federal Government.

- Currently, research dedicated to pancreatic cancer receives a mere 2 percent of the Federal dollars distributed by the NCI. By contrast, the other four of the top five cancer killers in the United States (lung, colon, breast and prostate cancer) received 2.8 to 6.3 fold more NCI funding in 2009 than pancreatic cancer.

- The average dollar amount of basic research (R) grants in pancreatic cancer was 18 to 29 percent less than R grants for the other four top cancer killers. The R grant mechanisms are the mainstay of scientific discovery in cancer research.

- Training grant funding in pancreatic cancer decreased by 15 percent from 2008 to 2009, a decline larger than in any other leading cancer. Pancreatic cancer trainees were awarded between 2.4 and 6.5 fold less grant money in 2009 than young researchers studying the other four top cancer killers.

- American Recovery & Reinvestment Act (ARRA) funding represented a unique opportunity for the NCI to direct research monies toward the deadliest cancers, including pancreatic cancer. Unfortunately, this opportunity was missed, as pancreatic cancer research received only slightly more than 1 percent of the NCI ARRA budget.

As has been noted by this Subcommittee and others in Congress in recent years, what is lacking is a well-defined, long-term comprehensive strategic plan in place to: advance the understanding of the biology of pancreatic cancer, examine its natural history and the genetic and environmental factors that contribute to its development; expand research on ways to screen and detect pancreatic cancer in much earlier stages; and launch innovative clinical trials to test targeted therapeutics and novel agents that will extend the survival and improve the quality of life of patients.

In addition, there must be a robust and sustained commitment of resources by the NCI and its sister institutes and centers at the National Institutes of Health (NIH).

Thanks to you and your colleagues, Mr. Chairman, and under the leadership of Dr. Harold Varmus, NCI has taken some encouraging steps in the right direction.

In 2010 NCI convened an internal group to develop an action plan for pancreatic cancer research and training. NCI brought together pancreatic cancer researchers and program staff from within the Institute to form the Pancreatic Cancer Action Planning Group, charged with developing an Action Plan that summarizes the fiscal

year 2011 research and training portfolio and identifies research gaps and opportunities for collaboration within NCI and with other members of the National Cancer Program, including advocacy groups, academia, and industry. This Action Plan was developed based on discussions at a Planning Group meeting held in July 2010 and continued interactions following the meeting. While it was not the long-term comprehensive strategic plan that we would still like to see the NCI develop for pancreatic cancer, we do believe that it was a good first step.

In addition to the initiatives and activities already included in the fiscal year 2011 portfolio, the Planning Group identified several opportunities for NCI to advance pancreatic cancer research. Emphasis was placed on activities with a high likelihood of improving survival rates, which have remained low despite improvements in many other cancer types. It was recognized that given the range of research conducted within and funded by NCI, the Institute is uniquely poised to support activities and provide services that other stakeholders are unable or unwilling to do. The Planning Group identified several opportunities for collaboration with advocacy organizations and the private sector to gain momentum in pancreatic cancer research.

The Action Plan reviewed the research activities that were planned for fiscal year 2011. We look forward to hearing from the NCI about the outcome of these plans. It also identified a few potential new initiatives such as a program announcement for R01 grants focused on pancreatic cancer. We strongly believe that a program announcement would be a positive step in the right direction and would urge you to find ways to encourage NCI to implement this idea. We hope to have the opportunity to work with NCI to implement the steps outlined in the plan.

Some ideas that emerged—such as promoting interaction and increased use of existing resources—will likely involve only modest financial investment, while others, like new program announcements, will require more resources. We therefore join with our colleagues in the One Voice Against Cancer (OVAC) coalition in highlighting the important role that NCI plays in our economy and in cancer research worldwide and ask this Committee to do everything in its power to safe-guard and expand this important resource.

Mr. Chairman, research is the only hope. We ask that you strongly urge the National Cancer Institute to put in place a long-term comprehensive strategic plan for pancreatic cancer research and ensure that there is funding available to implement that plan.

Thank you.

PREPARED STATEMENT OF THE PHYSICIAN ASSISTANT EDUCATION ASSOCIATION

On behalf of its membership, the 156 accredited physician assistant (PA) education programs in the United States, the Physician Assistant Education Association (PAEA) is pleased to submit these comments on the fiscal year 2012 appropriations for PA education programs that are authorized through Title VII of the Public Health Service Act.

PAEA is a member of the Health Professions and Nursing Education Coalition (HPNEC) and we support the HPNEC recommendation for funding of at least \$762.5 million in fiscal year 2012 for the health professions education programs authorized under Title VII and VIII of the Public Health Service Act and administered through the Health Resources and Services Administration (HRSA). HPNEC is an informal alliance of more than 60 national organizations representing schools, programs, health professionals, and students and dedicated to ensuring that the healthcare workforce is trained to meet the needs of the country's growing, aging, and diverse population.

Need for Increased Federal Funding

Faculty development is one of the profession's critical needs. In order to attract the best qualified to teaching, PA education programs must have the resources to train faculty in academic skills, such as curriculum development, teaching methods, and laboratory instruction. The challenges of teaching are broad and varied and include understanding different pedagogical theories, writing instructional objectives, and learning and applying educational technology. Most educators come from clinical practice and these skills are essential to transitioning to teaching. Educators are a critical element of meeting the Nation's demand for an increased supply of primary care clinicians.

Generalist training, workforce diversity, and practice in underserved areas are key priorities identified by HRSA. It is increasingly important that the health workforce better represents America's changing demographics, as well as addresses the issues of disparities in healthcare. PA programs have been successful in attracting

students from underrepresented minority groups and disadvantaged backgrounds. Studies have found that health professionals from underserved areas are three to five times more likely to return to underserved areas to provide care.

Physician Assistant Practice

Physician assistants (PAs) are licensed health professionals who practice medicine as members of a team with their supervising physicians. PAs exercise autonomy in medical decisionmaking and provide a broad range of medical and therapeutic services to diverse populations in rural and urban settings. In all 50 States, PAs carry out physician-delegated duties that are allowed by law and within the physician's scope of practice and the PA's training and experience. Additionally, PAs are delegated prescriptive privileges by their physician supervisors in all 50 States, the District of Columbia, and Guam. This allows PAs to practice in rural, medically underserved areas where they are often the only full-time medical provider.

Physician Assistant Education

There are currently 156 accredited PA education programs in the United States—a growth of 22 percent in less than 5 years; together these programs graduate nearly 6,000 PA students each year. PAs are educated as generalists in medicine; their flexibility allows them to practice in more than 60 medical and surgical specialties. More than one-third of PA program graduates practice in primary care.

The average PA education program is 27 months in length. Typically, 1 year is devoted to classroom study and approximately 15 months is devoted to clinical rotations. The typical curriculum includes 400 hours of basic sciences and nearly 600 hours of clinical medicine.

As of today, approximately 20 programs are in the pipeline at various stages of development, moving toward accredited status. The growth rate in the applicant pool is even more remarkable. In March 2006, there were a total of 7,608 applicants to PA education programs; as of March 2011, there were 16,112 applicants to PA education programs. This represents a 112 percent increase in Centralized Application Service (CASPA) applicants over the past 5 years.

The PA profession is expected to continue to grow as a result of the projected shortage of physicians and other healthcare professionals, the growing demand for professionals from an aging population, and the continuing strong PA applicant pool, which has grown by more than 10 percent each year since the year 2000. The Bureau of Labor Statistics projects a 39 percent increase in the number of PA jobs between 2008 and 2018. With its relatively short initial training time and the flexibility of generalist-trained PAs, the PA profession is well-positioned to help fill projected shortages in the numbers of healthcare professionals.

The continued growth of the profession heightens the need for additional resources to help meet the challenges of recruiting qualified faculty, shortages of preceptors and clinical sites, and increasing the diversity of faculty and program applicants.

Title VII Funding

Title VII funding is the only opportunity for PA programs to apply for Federal funding and plays a crucial role in developing and supporting PA education programs.

Title VII funding fills a critical need for curriculum development and faculty development. Funding enhances clinical training and education, assists PA programs with recruiting applicants from minority and disadvantaged backgrounds, and funds innovative programs that focus on educating a culturally competent workforce. Title VII funding increases the likelihood that PA students will practice in medically underserved communities with health professional shortages. The absence of this funding would result in the loss of care to patients in underserved areas.

Title VII support for PA programs has been strengthened with the enactment of the Patient Protection and Affordable Health Care Act (Public Law 111–148), which provides a 15 percent carve out in the appropriations process for PA programs. This funding will enhance capabilities to train a growing PA workforce and is likely to increase the pool for faculty positions as a result of PA programs now being eligible for faculty loan repayment. Huge loan burdens serve as barriers for physician assistant entry into academia.

Here we provide several examples of how PA programs have used Title VII funds to creatively expand care to underserved areas and populations, as well as to develop a diverse PA workforce.

—One Texas program has used its PA training grant to support the program at a distant site in an underserved area. This grant provides assistance to the program for recruiting, educating, and training PA students in the largely Hispanic

South Texas and mid-Texas/Mexico border areas and supports new faculty development.

- A Utah program has used its PA training grant to promote interprofessional teams—an area of strong emphasis in the Patient Protection and Affordable Care Act. The grant allowed the program to optimize its relationship with three service-learning partners, develop new partnerships with three service-learning sites, and create a model geriatric curriculum that includes didactic and clinical education.
- An Alabama program used its PA training grant to update and expand the current health behavior educational curriculum and HIV/STD training. They were also able to include PA students from other programs who were interested in rural, primary care medicine for a 4-week comprehensive educational program in HIV disease diagnosis and management.
- A South Carolina program has developed a model program that offers a 2-year academic fellowship for recent PA graduates with at least one year of clinical experience. To further enhance an evidence-based approach to education and practice, two specific evidence-based practice projects were embedded in the fellowship experience. Fellows direct and evaluate PA students' involvement in the "Towards No Tobacco" curriculum, aimed at fifth graders, and the PDA Patient Data experience, aimed at assessing healthcare services.

Recommendations on fiscal year 2012 Funding

The Physician Assistant Education Association requests the Appropriations Committee to support funding for Title VII and VIII health professions programs at a minimum of \$762.5 million for fiscal year 2012. This level of funding is crucial to support the Nation's demand for primary care practitioners, particularly those who will practice in medically underserved areas and serve vulnerable populations. Additionally we encourage support for the new programs and responsibilities contained in the Patient Protection and Affordable Care Act (Public Law 111-148), including a minimum of \$10 million to support PA education programs. We thank the members of the subcommittee for their support of the health professions and look forward to your continued support of solutions to the Nation's health workforce shortage. We appreciate the opportunity to present the Physician Assistant Education Association's fiscal year 2012 funding recommendation.

PREPARED STATEMENT OF POLICYLINK, THE FOOD TRUST, AND THE REINVESTMENT FUND

Chairman and distinguished Senators of the Committee, thank you for the opportunity to share our support for a Healthy Food Financing Initiative (HFFI). PolicyLink is a national research and action institute advancing economic and social equity by Lifting Up What Works®; The Food Trust is a nonprofit organization working to ensure that everyone has access to affordable, nutritious food; and The Reinvestment Fund is a Community Development Financial Institution that creates wealth and opportunity for low-wealth people and places through the promotion of socially and environmentally responsible development.

Our three organizations, along with a diverse coalition of stakeholders, which includes representatives from the grocery industry, health, civil rights, agriculture and the community development finance community, support the creation of HFFI to address the problem of "food deserts" in urban and rural areas across the Nation. This problem can be solved in many communities using a successful model that is underway in the State of Pennsylvania and is now being replicated throughout the country.

HFFI is a program worthy of investment as it promotes health, creates jobs and sparks economic development. HFFI will provide loan and grant financing to attract grocery stores and other fresh food retail to underserved urban, suburban, and rural areas, and renovate and expand existing stores so they can provide the healthy foods that communities want and need. Over time, with continued investment, HFFI could solve the problem of food deserts in urban and rural communities across the country.

For decades, low-income communities, particularly communities of color, have suffered from a lack of access to healthy, fresh food. USDA research determined that more than 23.5 million Americans are living in communities without access to high-quality, fresh food. Studies repeatedly show that residents of many low-income neighborhoods must travel long distances for healthy food, or rely on corner stores and fast food outlets offering high fat, high sugar foods. For instance, a recent multistate study found that low-income census tracts had half as many super-

markets as wealthy tracts, and four times as many smaller grocery stores. Another multistate study found that 8 percent of African Americans live in a tract with a supermarket, compared to 31 percent of whites. Nationally, low-income zip codes have 30 percent more convenience stores, which tend to lack healthy food, than middle income zip codes.

And, a nationwide analysis found there are 418 rural food desert counties where all residents live more than 10 miles from a supermarket or a supercenter—this is 20 percent of rural counties. In rural communities, inadequate transportation can be a particular challenge. In Mississippi, which has the highest obesity rate of any State, over 70 percent of food stamp eligible households travel more than 30 miles to reach a supermarket. Adults living in rural Mississippi food desert counties are 23 percent less likely to consume the recommended fruits and vegetables than those in counties that have supermarkets, controlling for age, sex, race, and education.

Controlling for population density, rural areas have fewer food retailers of any types compared to urban areas, and only 14 percent the number of chain supermarkets. For instance, in New Mexico, rural residents have access to fewer grocery stores than urban residents, pay more for comparable items, and have less selection. The same market basket of groceries costs \$85 for rural residents versus \$55 for urban residents.

The results of this lack of healthy food options are grim—these communities have significantly higher rates of obesity, diabetes, and other related health issues. Over the past decade, obesity rates have more than doubled in children and tripled in adolescents. In 2010, PolicyLink and The Food Trust conducted a review of more than 130 studies on the issue of access to healthy food and found a direct correlation between diet-related diseases and access. A California study found that obesity and diabetes rates were 20 percent higher for those living in the least healthy “food environments.” In Indianapolis, a study found that BMI values corresponded with access to supermarkets and fast food restaurants. Researchers estimated that adding a new grocery store to a high poverty neighborhood translates into a 3 pound weight decrease.

Fortunately, changing access changes eating habits. For every additional supermarket in a census tract, produce consumption increases 32 percent for African Americans and 11 percent for whites, according to a multistate study. A survey of produce availability in New Orleans’ small neighborhood stores found that for each additional meter of shelf space devoted to fresh vegetables, residents eat an additional .35 servings per day. In fact, of 14 studies that examine food access and consumption of healthy foods, all but one of them found a correlation between greater access and better eating behaviors. This is also true for food stamp recipients. Proximity to a supermarket was found to be associated with increased fruit and vegetable consumption.

The problems associated with lack of access go beyond health. Low-income communities are cut off from all the economic development benefits that come with a local grocery store: the creation of steady jobs at decent wages and the sparking of complementary retail stores and services nearby. Grocery stores operate as important economic anchors for communities, providing a vital service and bringing customers that can also support other nearby business. Securing new or improved local grocery stores can improve local economies and create jobs.

President Barack Obama’s proposed fiscal year 2012 budget includes a proposal to invest \$330 million, including \$250 million in New Markets Tax Credits, in a national HFFI. Specifically, the initiative would provide:

- \$35 million through USDA’s Office of the Secretary, with additional “other funds of Rural Development and the Agricultural Marketing Service available to support the USDA’s portion of the Healthy Food Financing Initiative”;
- \$25 million through the Treasury Department’s CDFI Fund;
- \$20 million through Health and Human Services; and
- \$250 million through the Treasury Department’s New Markets Tax Credits Program.

A Healthy Food Financing Initiative would attract investment in underserved communities by providing critical loan and grant financing. These one-time resources will help fresh food retailers overcome the higher initial barriers to entry into underserved, low-income urban and rural communities, and would also support renovation and expansion of existing stores so they can provide the healthy foods that communities want and need. The program would be flexible and comprehensive enough to support innovations in healthy food retailing and to assist retailers with different aspects of the store development and renovation process.

Grocery industry representatives find that there are obstacles to grocery store development in underserved low-income communities, but also that those obstacles can be overcome. The development process for building a new grocery store is

lengthy and complex, and retailers often find that stores in low-income communities have high start-up costs, appropriate sites are hard to find, and securing financing is difficult. Grocery operators in both urban and rural areas cite lack of access to flexible financing as one of the top barriers hindering the development of stores in underserved areas.

HFFI is modeled after the successful Pennsylvania Fresh Food Financing Initiative (FFFI), a public/private partnership launched in 2004. Using a State investment of \$30 million, the program has led to:

- projects totaling more than \$190 million;
- 88 stores built or renovated in underserved communities in urban and rural areas across the State;
- improved access to healthy food for more than 400,000 residents;
- more than 5,000 jobs created or retained;
- increased local tax revenues; and
- much-needed additional economic development in these communities.

Stores range from full-service 70,000 square foot supermarkets to 900 square food shops; and from traditional grocery stores to farmers' markets, cooperatives, and corner stores selling healthy food. Approximately two-thirds of the projects were in rural areas and small towns with the remainder in urban areas.

HFFI is a viable, effective, and economically sustainable solution to the problem of limited access to healthy foods. It can bring triple bottomline benefits, achieving multiple goals: reducing health disparities and improving the health of families and children; creating jobs; and, stimulating local economic development in low-income communities.

HFFI would incorporate the key components that allowed the Pennsylvania program to be so effective at attracting private dollars, garnering the commitment of store operators, getting fresh food retail stores and markets successfully developed, and stimulating local economies.

The Pennsylvania FFFI has been cited as an innovative model by the U.S. Centers for Disease Control and Prevention, the National Conference of State Legislatures, Harvard's Kennedy School of Government, and the National Governors Association. There is significant momentum in many States and cities across the country to address the lack of grocery access in underserved communities. Several States and/or cities are in the process of replicating the successful Pennsylvania Fresh Food Financing Initiative Program, and many others have begun to examine the needs and opportunities in their communities. For example:

- The State of New York has launched the Healthy Food, Healthy Communities Initiative, a business financing program to encourage supermarket and other fresh food retail investment in underserved areas throughout the State that will provide loans and grants to eligible projects. New York City has launched a complementary FRESH program that will encourage supermarket development through tax and zoning incentives and a single point of access to city government for supermarket operators.
- The City of New Orleans recently launched the Fresh Food Retailer Initiative Program (FFRI) that will provide direct financial assistance to retail businesses by awarding forgivable and/or low-interest loans to grocery stores and other fresh food retailers.
- The California Endowment, NCB Capital Impact, and other community, supermarket industry, and government partners have been working to create a supermarket financing program in California that is expected to be launched in the first half of 2011.

A national Healthy Food Financing Initiative could amplify the impact in each of these States and leverage the work already underway to ensure swift implementation. Moreover, a national HFFI would insure that all State and communities could solve their food desert problems with new stores and other healthy food retail projects.

In the midst of our current economic downturn, the need for a comprehensive Federal policy to address the lack of fresh food access in low-income is critical. We urge the Committee to support full funding for a Healthy Food Financing Initiative, for the benefit of communities across the Nation. Thank you for the opportunity to share our perspectives with you today. If you should need additional information about HFFI please contact Judith Bell from PolicyLink (Judith@policylink.org), Pat Smith from The Reinvestment Fund (patricia.smith@trffund.org), or John Weidman from The Food Trust (Jweidman@thefoodtrust.org)

PREPARED STATEMENT OF THE POPULATION ASSOCIATION OF AMERICA/ASSOCIATION
OF POPULATION CENTERS

Background on the PAA/APC and Demographic Research

The Population Association of America (PAA) is a scientific organization comprised of over 3,000 population research professionals, including demographers, sociologists, statisticians, and economists. The Association of Population Centers (APC) is a similar organization comprised of over 40 universities and research groups that foster collaborative demographic research and data sharing, translate basic population research for policy makers, and provide educational and training opportunities in population studies. Population research centers are located at public and private research institutions nationwide.

Demography is the study of populations and how or why they change. Demographers, as well as other population researchers, collect and analyze data on trends in births, deaths, and disabilities as well as racial, ethnic, and socioeconomic changes in populations. Major policy issues population researchers are studying include the demographic causes and consequences of population aging, trends in fertility, marriage, and divorce and their effects on the health and well being of children, and immigration and migration and how changes in these patterns affect the ethnic and cultural diversity of our population and the Nation's health and environment.

The NIH mission is to support research that will improve the health of our population. The health of our population is fundamentally intertwined with the demography of our population. Recognizing the connection between health and demography, the NIH supports extramural population research programs primarily through the National Institute on Aging (NIA) and the National Institute of Child Health and Human Development (NICHD).

National Institute on Aging

According to the Census Bureau, by 2029, all of the baby boomers (those born between 1946 and 1964) will be age 65 years and over. As a result, the population age 65–74 years will increase from 6 percent to 10 percent of the total population between 2005 and 2030. This substantial growth in the older population is driving policymakers to consider dramatic changes in Federal entitlement programs, such as Medicare and Social Security, and other budgetary changes that could affect programs serving the elderly. To inform this debate, policymakers need objective, reliable data about the antecedents and impact of changing social, demographic, economic, and health characteristics of the older population. The NIA Division of Behavioral and Social Research (BSR) is the primary source of Federal support for research on these topics.

In addition to supporting an impressive research portfolio, that includes the prestigious Centers of Demography of Aging and Roybal Centers for Applied Gerontology Programs, the NIA BSR program also supports several large, accessible data surveys. One of these surveys, the Health and Retirement Study (HRS), has become one of the seminal sources of information to assess the health and socioeconomic status of older people in the United States. Since 1992, the HRS has tracked 27,000 people, providing data on a number of issues, including the role families play in the provision of resources to needy elderly and the economic and health consequences of a spouse's death. HRS is particularly valuable because its longitudinal design allows researchers: (1) the ability to immediately study the impact of important policy changes such as Medicare Part D; and (2) the opportunity to gain insight into future health-related policy issues that may be on the horizon, such as HRS data indicating an increase in pre-retirees self-reported rates of disability. In August 2011, HRS will release genotyping data, enhancing the ability of researchers to track the onset and progression of diseases and conditions affecting the elderly.

Currently, the NIA is paying grant applications requesting less than \$500,000 in direct costs through the 11th percentile, while grants seeking \$500,000 or more are being paid through the 8th percentile—making it one of the lowest paylines at NIH. As research costs increase, NIA faces the prospect of funding fewer grants to sustain larger ones in its commitment base. With additional support in fiscal year 2012, the NIA BSR program could fully fund its large-scale projects, including the existing centers programs and ongoing surveys, without resorting to cost cutting measures, such as cutting sample size, while continuing to support smaller investigator initiated projects

Eunice Kennedy Shriver National Institute on Child Health and Human Development

Since its establishment in 1968, the Eunice Kennedy Shriver NICHD Center for Population Research has supported research on population processes and change. Today, this research is housed in the Center's Demographic and Behavioral Sciences Branch (DBSB). The Branch encompasses research in four broad areas: family and fertility, mortality and health, migration and population distribution, and population composition. In addition to funding research projects in these areas, DBSB also supports a highly regarded population research infrastructure program and a number of large database studies, including the National Longitudinal Study of Adolescent Health (Add Health), Panel Study of Income Dynamics, and National Longitudinal Study of Youth.

NIH-funded demographic research has consistently provided critical scientific knowledge on issues of greatest consequence for American families: work-family conflicts, marriage and childbearing, childcare, and family and household behavior. However, in the realm of public health, demographic research is having an even larger impact, particularly on issues regarding adolescent and minority health. Understanding the role of marriage and stable families in the health and development of children is another major focus of the NICHD DBSB. Consistently, research has shown children raised in stable family environments have positive health and development outcomes. Policymakers and community programs can use these findings to support unstable families and improve the health and well being of children.

One of the most important programs the NICHD DBSB supports is the Population Research Infrastructure Program (PRIP). Through PRIP, research is conducted at private and public research institutions nationwide. The primary goal of PRIP is "to facilitate interdisciplinary collaboration and innovation in population research, while providing essential and cost-effective resources in support of the development, conduct, and translation of population research." Population research centers supported by PRIP are focal points for the demographic research field where innovative research and training activities occur and resources, including large-scale databases, are developed and maintained for widespread use.

With additional support in fiscal year 2012, NICHD could sustain full funding to its large-scale surveys, which serve as a resource for researchers nationwide. Furthermore, the Institute could apply additional resources toward improving its funding pipeline, which has fallen from the 13th percentile in fiscal year 2010 to the 11th percentile in fiscal year 2011. Additional support could be used to support and stabilize essential training and career development programs necessary to prepare the next generation of researchers and to support and expand proven programs, such as PRIP.

National Center for Health Statistics

Located within the Centers for Disease Control (CDC), the National Center for Health Statistics (NCHS) is the Nation's principal health statistics agency, providing data on the health of the U.S. population and backing essential data collection activities. Most notably, NCHS funds and manages the National Vital Statistics System, which contracts with the States to collect birth and death certificate information. NCHS also funds a number of complex large surveys to help policy makers, public health officials, and researchers understand the population's health, influences on health, and health outcomes. These surveys include the National Health and Nutrition Examination Survey (NHANES), National Health Interview Survey (HIS), and National Survey of Family Growth. Together, NCHS programs provide credible data necessary to answer basic questions about the state of our Nation's health.

Despite recent steady funding increases, NCHS continues to feel the effects of long-term funding shortfalls, compelling the agency to undermine, eliminate, or further postpone the collection of vital health data. For example, in 2009, sample sizes in HIS and NHANES were cut, while other surveys, most notably the National Hospital Discharge Survey, were not fielded. In 2009, NCHS proposed purchasing only "core items" of vital birth and death statistics from the States (starting in 2010), effectively eliminating three-fourths of data routinely used to monitor maternal and infant health and contributing causes of death. Fortunately, Congress and the new Administration worked together to give NCHS adequate resources and avert implementation of these draconian measures. Nonetheless, the agency continues to operate in a precarious state.

The Administration recommends NCHS receive \$161.9 million in fiscal year 2011; however, ultimately, the agency received \$23.2 million less than the Administration requested. This reduced amount has postponed important initiatives to, for example,

re-engineer collection of the Nation's vital statistics, using standard birth and death certificate items.

PAA and APC, as members of The Friends of NCHS, support the Administration's request for fiscal year 2012, \$162 million, in hopes many initiatives proposed by the Administration in fiscal year 2011 can proceed, including an effort to fully support electronic birth records in all 50 States.

Bureau of Labor Statistics

During these turbulent economic times, data produced by the Bureau of Labor Statistics (BLS) are particularly relevant and valued. PAA and APC members have relied historically on objective, accurate data from the BLS. In recent years, our organizations have become increasingly concerned about the state of the agency's funding.

We are pleased the Administration has requested BLS receive a total of \$647 million in fiscal year 2012. According to the agency, this funding level would enable BLS, for example, to add the Contingent Work Supplement to the Current Population Survey, making more data available on changing workplace arrangements and continue its work on developing an alternative poverty measure.

Summary of fiscal year 2012 Recommendations

In sum, the PAA and APC support the Administration's fiscal year 2012 request for the National Institutes of Health, National Center for Health Statistics and the Bureau of Labor Statistics. With respect to the NIH, however, we support the Administration's request as a floor and encourage the Subcommittee to consider providing the NIH with funding as high as \$35 billion. This amount, endorsed by the Ad Hoc Group for Medical Research, reflects not only inflation, but also the additional investment needed to sustain the new research capacity created by the American Recovery and Reinvestment Act.

Thank you for considering our requests and for supporting Federal programs that benefit the population sciences.

PREPARED STATEMENT OF PREVENT BLINDNESS AMERICA

FUNDING REQUEST OVERVIEW

Prevent Blindness America appreciates the opportunity to submit written testimony for the record regarding fiscal year 2012 funding for vision and eye health related programs. As the Nation's leading nonprofit, voluntary health organization dedicated to preventing blindness and preserving sight, Prevent Blindness America maintains a long-standing commitment to working with policymakers at all levels of government, organizations and individuals in the eye care and vision loss community, and other interested stakeholders to develop, advance, and implement policies and programs that prevent blindness and preserve sight. Prevent Blindness America respectfully requests that the Subcommittee provide the following allocations in fiscal year 2012 to help promote eye health and prevent eye disease and vision loss:

- Provide at least \$3.23 million to maintain vision and eye health efforts at the Centers for Disease Control and Prevention (CDC).
- Support the Maternal and Child Health Bureau's (MCHB) National Center for Children's Vision and Eye Health (Center).
- Provide additional resources for the National Eye Institute (NEI).

INTRODUCTION AND OVERVIEW

Vision-related conditions affect people across the lifespan from childhood through elder years. Good vision is an integral component to health and well-being, affects virtually all activities of daily living, and impacts individuals physically, emotionally, socially, and financially. Loss of vision can have a devastating impact on individuals and their families. An estimated 80 million Americans have a potentially blinding eye disease, 3 million have low vision, more than 1 million are legally blind, and 200,000 are more severely visually blind. Vision impairment in children is a common condition that affects 5 to 10 percent of preschool age children. Vision disorders (including amblyopia ("lazy eye"), strabismus ("cross eye"), and refractive error) are the leading cause of impaired health in childhood.

Alarmingly, while half of all blindness can be prevented through education, early detection, and treatment, the NEI reports that "the number of Americans with age-related eye disease and the vision impairment that results is expected to double

within the next three decades.”¹ Among Americans age 40 and older, the four most common eye diseases causing vision impairment and blindness are age-related macular degeneration (AMD), cataract, diabetic retinopathy, and glaucoma.² Refractive errors are the most frequent vision problem in the United States—an estimated 150 million Americans use corrective eyewear to compensate for their refractive error.² Uncorrected or under-corrected refractive error can result in significant vision impairment.²

To curtail the increasing incidence of vision loss in America, Prevent Blindness America advocates sustained and meaningful Federal funding for programs that help promote eye health and prevent eye disease, vision loss, and blindness; needed services and increased access to vision screening; and vision and eye disease research. We thank the Subcommittee for its consideration of our specific fiscal year 2012 funding requests, which are detailed below.

VISION AND EYE HEALTH AT THE CDC: HELPING TO SAVE SIGHT AND SAVE MONEY

The CDC serves a critical national role in promoting vision and eye health. Since 2003, the CDC and Prevent Blindness America have collaborated with other partners to create a more effective public health approach to vision loss prevention and eye health promotion. The CDC works to:

- Promote eye health and prevent vision loss.
- Improve the health and lives of people living with vision loss by preventing complications, disabilities, and burden.
- Reduce vision and eye health related disparities.
- Integrate vision health with other public health strategies.

Integrating Vision Health into Broader Disease Prevention and Health Promotion Efforts

One of the cornerstone activities of the vision and eye health work at the CDC is its support and encouragement of efforts to better integrate State-level initiatives to address vision and eye disease by approaching vision health through other public health prevention, treatment, and research efforts. Vision loss is associated with a myriad of other serious chronic, life threatening, and disabling conditions, including diabetes, depression, unintentional injuries, and other health problems and behavioral risk factors such as tobacco use. Leveraging scarce resources and recognizing the numerous connections between eye health and other diseases, the CDC works to integrate and connect vision health initiatives to other State, local, and community health programs.

To advance State-based vision health integration, CDC funds are supporting a joint effort between the New York State Department of Health and Prevent Blindness Tri-State, focused on integrating vision-related services at the State and local level. Working together, these partners are promoting vision loss prevention strategies within the State Department of Health. One initiative resulting from this partnership has been the launch of a statewide tobacco cessation media campaign highlighting the impact of smoking on potential vision loss. Other examples include State-based programs to prevent and reduce diabetes, including efforts to educate patients and healthcare providers of the relationship between diabetes and certain eye problems, such as diabetic retinopathy and cataracts. A similar effort has recently been initiated in Texas.

The goal of these integration efforts is to ensure that vision loss and eye health promotion are incorporated into all relevant local, State, and Federal public health interventions, prevention and treatment programs, and other initiatives that impact causes of—and factors that contribute to—vision problems and blindness. By integrating efforts and coordinating approaches in this manner, Federal and State resources will be used more efficiently, eye health problems and vision loss can be reduced, and the overall health and well-being of individuals and communities will be improved.

Identifying and Preventing Vision Problems through Community-Based Strategies

The CDC supports private sector efforts to develop and evaluate better ways to identify and treat individuals with potential eye disease, vision loss, and other ocular conditions. Among other efforts, CDC funding is currently supporting:

- A study to assess the overall effectiveness and costs associated with implementing an adult vision and eye health history and risk assessment/referral program. This study, being conducted by Johns Hopkins University, in partner-

¹“Vision Problems in the U.S.: Prevalence of Adult Vision Impairment and Age-Related Eye Disease in America,” Prevent Blindness America and the National Eye Institute, 2008.

²Ibid.

ship with Prevent Blindness Ohio, is working in collaboration with the Physician's Free Clinic in Columbus, Ohio and Akron Community Health Resources to investigate the best methods for identifying patients who need eye care services and providing linkages to follow-up care.

- An initiative spearheaded by Duke University and Prevent Blindness North Carolina to evaluate the benefit of pediatric and school-based vision screening. The project identified the need to ensure proper ongoing training and education of pediatricians on vision screening. In collaboration with the American Board of Pediatrics, the project has developed maintenance of certification module to improve office-based preschool vision screening.

Data Collection

Understanding the breadth and depth of vision and eye health issues across the Nation is paramount to ensuring appropriate allocation of resources and effective deployment of targeted interventions. Thus, the CDC supports programs and systems that collect, evaluate, and disseminate critical vision health data.

- The CDC developed the first optional Behavioral Risk Factor Surveillance System (BRFSS)³ vision module, which collects State-based information on access to eye care and the prevalence of eye disease and eye injury. Early in 2011, the CDC will publish a report describing visual impairment as a serious public health issue affecting more than 2.9 million Americans. Unfortunately, in part due to insufficient funding, only 19 States currently use the vision module; this lack of broad adoption precludes the CDC, Congress, and other stakeholders from having the information they need to understand and address the full scope of vision loss and eye health problems facing the Nation.
- CDC funding is supporting a joint endeavor between Duke University and Prevent Blindness America to conduct a systematic evidence review to describe the delivery systems of vision-related services and to identify new areas for policy evaluation or clinical research. This information will help identify the most at-risk populations and highlight gaps in care and service delivery to ensure that public and private resources are allocated to areas of greatest need.

To that end, Prevent Blindness America respectfully requests the Subcommittee provide a \$3.23 million allocation for vision and eye health initiatives at the CDC. This level of investment will help the CDC sustain its efforts to address the growing public health threat of preventable vision loss among at-risk and underserved populations. Fiscal year 2012 resources will support strengthened State-based public health integration efforts to address vision and eye health and the development of additional evidence-based public health interventions that improve eye health among the Nation's most at-risk and underserved.

INVESTING IN THE VISION OF OUR NATION'S MOST VALUABLE RESOURCE—CHILDREN

While the risk of eye disease increases after the age of 40, eye and vision problems in children are of equal concern. If left untreated, they can lead to permanent and irreversible visual loss and/or cause problems socially, academically, and developmentally. Although more than 12.1 million school-age children have some form of a vision problem, only one-third of all children receive eye care services before the age of six.⁴

In 2009, the Maternal and Child Health Bureau established the National Center for Children's Vision and Eye Health, a national vision health collaborative effort aimed at developing the public health infrastructure necessary to promote eye health and ensure access to a continuum of eye care for young children. Prevent Blindness America is requesting ongoing support for the National Center for Children's Vision and Eye Health.

With this support the Center, will continue to:

- Provide national leadership in the development of best practices and guidelines for public health infrastructure, national vision screening guidelines, and statewide strategies that ensure early detection, vision screening, and a continuum of vision and eye healthcare for children.
- Determine mechanisms for advancing State-based performance improvement systems, screening guidelines, and a mechanism for uniform data collection and reporting.
- Collaborate with States to develop and implement statewide strategies for vision screening, establish quality improvement strategies, and determine mecha-

³BRFSS is a State-based system of health surveys that collects information on chronic disease and injury.

⁴"Our Vision for Children's Vision: A National Call to Action for the Advancement of Children's Vision and Eye Health, Prevent Blindness America," Prevent Blindness America, 2008.

nisms for the improvement of data systems and reporting of children's vision and eye health services.

ADVANCE AND EXPAND VISION RESEARCH OPPORTUNITIES

Prevent Blindness America calls upon the Subcommittee to provide additional support for the NEI to bolster its efforts to identify the underlying causes of eye disease and vision loss, improve early detection and diagnosis of eye disease and vision loss, and advance prevention and treatment efforts. Research is critical to ensure that new treatments and interventions are developed to help reduce and eliminate vision problems and potentially blinding eye diseases facing consumers across the country. In 2009, Congress commended the NEI's leadership in basic and translational research through H. Res. 366 and S. Res. 209 (111th Congress), which recognized NEI's 40 years as the National Institutes of Health (NIH) Institute that leads the Nation's commitment to save and restore vision. The Resolutions also designated 2010–2020 as the Decade of Vision in recognition of the increasing health and economic burden of eye disease, mainly as a result of an aging population.

Through additional support, the NEI will be able to continue to grow its efforts to:

- Expand capacity for research, as demonstrated by the significant number of high-quality grant applications submitted in response to American Recovery and Reinvestment Act opportunities.
- Address unmet need, especially for programs of special promise that could reap substantial downstream benefits.
- Fund research to reduce healthcare costs, increase productivity, and ensure the continued global competitiveness of the United States.

By providing additional funding for the NEI at the NIH, essential efforts to identify the underlying causes of eye disease and vision loss, improve early detection and diagnosis of eye disease and vision loss, and advance prevention, treatment efforts and health information dissemination will be bolstered.

CONCLUSION

On behalf of Prevent Blindness America, our Board of Directors, and the millions of people at risk for vision loss and eye disease, we thank you for the opportunity to submit written testimony regarding fiscal year 2012 funding for the CDC's vision and eye health initiatives, the MCHB's National Center for Children's Vision and Eye Health, and the NEI. Please know that Prevent Blindness America stands ready to work with the Subcommittee and other Members of Congress to advance policies that will prevent blindness and preserve sight. Please feel free to contact us at any time; we are happy to be a resource to Subcommittee members and your staff. We very much appreciate the Subcommittee's attention to—and consideration of—our requests.

PREPARED STATEMENT OF PROLITERACY

Chairman Harkin, Ranking Member Shelby, and members of the Subcommittee, on behalf of the millions of adult learners working to improve their basic reading, writing, math, and computer skills and pursue greater economic opportunity for themselves and their families, thank you for the opportunity to provide written testimony regarding the President's fiscal year 2012 budget request for adult education and family literacy, provided for under the Workforce Investment Act, Title II. We would be pleased to testify and participate in any future hearings regarding adult literacy and basic education.

We strongly urge you to approve at the very least, the President's request of \$658.3 million for Adult Basic and Literacy Education in fiscal year 2012 to better assist the one in seven adults nationally who struggle with illiteracy. At a time when millions of Americans are struggling to find work, it is essential to invest in adult learning in order to put more American families on the road to self-sufficiency and economic security.

Background: ProLiteracy

ProLiteracy is the world's oldest and largest organization of adult literacy and basic education programs in the United States. ProLiteracy traces its roots to two premiere adult literacy organizations: Laubach Literacy International and Literacy Volunteers of America. In 2002, these two organizations merged to create ProLiteracy.

ProLiteracy represents more than 1,000 community-based organizations and adult basic education programs in the United States, and we partner with literacy organi-

zations in 50 developing countries. In communities across the United States, these organizations use trained volunteers, teachers, and instructors to provide one-on-one tutoring, classroom instruction, and specialized classes in reading, writing, math, technology, English language skills, job-training and workforce literacy skills, GED preparation, and citizenship. Our members are located in all 50 States and in the District of Columbia. Through education, training and advocacy, ProLiteracy supports the frontline work of these organizations with regional conferences and other training events; credentialing; and the publication of materials and products used to teach adults basic literacy and English-as-a-second-language and to prepare adults for the U.S. citizenship exam and GED Tests.

The Urgent Need to Invest in Adult Education

In 2003, the U.S. Department of Education conducted the National Assessment of Adult Literacy (NAAL) in order to gauge the English reading and comprehension skills of individuals in the United States over the age of 16 on daily literacy tasks such as reading a newspaper article, following a printed television guide, and completing a bank deposit slip. The results indicated that 30 million adults—14 percent of this country's adult population—had below basic literacy skills; that is, their ability to read was so poor, they could not complete a job application without help or follow the directions on a medicine bottle. An additional 63 million adults read only slightly better, for a total of 93 million American adults who are considered low literate.

Because under-educated adults are more likely to be unemployed and require public assistance, the high percentage of low-literate adults is having an adverse affect on our Nation's efforts to reduce unemployment and reduce the deficit. In 2009, 14.6 percent of those without a high school diploma were unemployed compared to 9.7 percent of high school graduates; 8.6 percent of those with some college; 6.8 percent with an associate's degree; 4.6 percent with a 4-year degree or more.¹ And the trends for these adults are not encouraging. For example, while 67 percent of the service industry's jobs in 1983 required a high school diploma or less, this percentage is expected to drop to zero by 2018.²

In addition, we will fail to meet President Obama's goal of once again leading the world in college degree attainment unless we support more adults without college degrees to enroll in post-secondary education. To meet the President's goal, it is estimated that the United States will need to move at least 3.4 million adults with high school diplomas but no college degrees into postsecondary education.³ Increasing the number of adults with high-school degrees or equivalents, and with the skills to succeed in college, will help us achieve this goal.

The bottom line is that a greater investment in adult education will increase employment and postsecondary enrollments, move individuals off of public assistance, and ultimately reduce the deficit.

Despite the critical role that adult education plays in reducing unemployment and increasing postsecondary attainment, the adult education system currently only has the capacity to serve approximately 2.5 million of these 93 million adults each year. Adult education has been basically flat funded for a decade, seeing only a modest overall increase from 2001–2010.⁴ In fiscal year 2011, the number of individuals served will almost certainly be reduced as a result of the \$32.1 million cut to Title II State grants in the final fiscal year 2011 CR. This cut comes at a time when many States are responding to drastically declining revenues by slashing budgets for education, training, and human services, including their investments in adult education.

The Proposed Adult Basic and Literacy Education Budget

The proposed fiscal year 2012 budget includes several significant features that we strongly support. First, the President requested \$635 million for State formula grants for adult education through the Workforce Investment Act (WIA), Title II, an increase of \$6.8 million compared to the 2010 appropriation. As we have discussed above, the need for increased investment in adult education is clear, and we welcome the President's call for a modest increase.

We recognize that in the current fiscal environment, the subcommittee will be reluctant to increase spending in many areas of the budget above this year's level. If an increase is not possible, it is critically important to hold spending for adult education and literacy at current levels. An additional cut to Title II funding on top

¹ <http://www.bls.gov/cps/cpsaat7.pdf>.

² http://cew.georgetown.edu/see/Figure_4.17_pg_86.

³ http://www.womeningovernment.org/files/onemillion_letter.pdf.

⁴ <http://www2.ed.gov/about/overview/budget/history/edhistory.pdf>.

of the \$31 million cut in fiscal year 2011 would be devastating to State adult education systems around the country, and, as we have noted, would likely increase unemployment and contribute to the deficit.

Workforce Innovation

The administration proposes to set aside \$50.8 million from the State formula funds to support a Workforce Innovation Fund (WIF), which will also include \$30 million in funding from the Rehabilitation Services and Disability Research account, and almost \$298 million from the Department of Labor.

ProLiteracy applauds the administration's commitment to innovation. We urge the Subcommittee to ensure that innovation funding will benefit adults at all skill levels, particularly the millions who are estimated to possess less than basic literacy skills served by community-based organizations. We suggest, in fact, competitive priority for proposals that will address those at the lowest levels of literacy and those with significant barriers to learning.

However, we also caution that after experiencing a dramatic cut to State formula funding in fiscal year 2011, care must be taken to ensure that State formula funding is sufficient to ensure the survival of existing programs. ProLiteracy urges the Subcommittee to ensure that the WIF, if it moves forward, is funded on top of annual WIA formula funds, rather than as a carve out of existing formula funds.

National Leadership

The President's proposal also includes an additional \$12 million for national leadership funds to the Department of Education that would be used to evaluate the impact of college bridge programs that assist adult learners in transitioning from adult basic education to postsecondary education and training, and for building greater technology infrastructure for adult learners and adult educators.

We believe these ideas reflect real needs in our field, and if these initiatives lead to new resources and better services on the ground for learners and the programs that serve them, than this could be a very positive development. Again, however, we would urge that any new programming that would not have an immediate, direct, benefit to adult learners not come at the expense of State formula funds.

WIA Reauthorization and Use of National Leadership Funds

The President's budget request also supports the reauthorization of WIA, and specifically calls for better alignment between Title I and Title II. We share the administration's desire for more streamlined service delivery systems that are more engaged with employers, and the promotion of innovative career pathways models—but in particular for those learners at the lowest levels of literacy.

We strongly urge, therefore, expanding funding opportunities for community-based programs that have successfully implemented strategies for delivering basic literacy instruction together with employment training so that they may document and disseminate best practices related to the integration of title I job training programs with title II adult literacy programs.

Through both reauthorization of the Workforce Investment Act and use of national leadership funding, we also recommend that the Department examine and publish successful strategies and best practices that can help adults with low literacy levels improve their overall skills and employment opportunities.

We note that learners at the lowest levels of literacy often receive literacy instruction at community-based organizations (CBOs) that utilize trained volunteers. For decades, volunteers, and other types of non-career instructors such as such as VISTA or AmeriCorps members, have been a vital component in the delivery of education services for adults with low literacy in the United States. Volunteers serve in non-instructional roles as well such as mentoring, counseling, recruiting students, and serving as teaching aides to paid instructors.

However, adult education career pathway programs are based largely on traditional career pathways programs that connect secondary and postsecondary students to further education and work in a specific industry. As a result, the limited existing research on career pathway approaches used with adult learners is largely focused on students with higher-level literacy skills.

We therefore urge the subcommittee to ensure that CBOs that utilize trained volunteers are integrated into the Department's career pathways strategies. We suggest that the Department identify and disseminate successful strategies and best practices that will assist community-based organizations that utilize adult literacy volunteers to support the Department's career pathways initiatives; and implement strategies to increase participation by community-based organizations that utilize trained volunteers in any related technical assistance efforts.

Thank you for the opportunity to present this testimony. We would be happy to respond to any questions that you may have.

PREPARED STATEMENT OF THE PROSTATITIS FOUNDATION

We are the unpaid volunteers at the Prostatitis Foundation representing thousands of men nationwide with prostatitis. Our mission for 15 years has been to:

- Educate the public about the prevalence of prostatitis by our website www.prostatitis.org, our newsletters, and newspaper and magazine articles. It is estimated that 10 percent of all males suffer from chronic prostatitis/pelvic pain syndrome (CP/PPS) and 50 percent of men will experience (CP/PPS) during their lifetime. Symptoms can include severe pelvic pain, urinary and sexual dysfunction and infertility. The possible connection of prostatitis to prostate cancer is uncertain and not adequately researched. Prostatitis is common in young men who are at an age where they are reluctant to discuss such personal matters as pelvic pain, voiding problems and sexual dysfunction with family, friends or co-workers. The result has been an unpublicized crisis and a costly, hopeless medical condition.
- Encourage research funding. We have worked with the NIH research team personnel and research centers over three sets of multi-year clinical trial programs going back to 1996. We are now assisting with the fourth group of nationwide research centers. The Map Network is a group of researchers who have been assembled by National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) to include specialties besides urology to get some basic scientific research that will lead to determining a cause and cure for (CP/PPS). Everyone has too much time and expense invested to let these efforts expire without pushing to complete this search for a cause and cure for (CP/PPS). If we do not build on the efforts of the three previous accumulations of data to determine a cause and cure it will be lost and the next group will have to start at the beginning again.

We request continuing funding and direction through The National Institutes of Health (NIH) to National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) who are overseeing this Map Network of research centers.

PREPARED STATEMENT OF THE PULMONARY HYPERTENSION ASSOCIATION

Mr. Chairman, thank you for the opportunity to submit testimony on behalf of the Pulmonary Hypertension Association (PHA).

I would like to extend my sincere thanks to the Subcommittee for your past support of pulmonary hypertension (PH) programs at the National Institutes of Health, Centers for Disease Control and Prevention, and Health Resources and Services Administration. These initiatives have opened many new avenues of promising research, helped educate hundreds of physicians in how to properly diagnose PH, and raised awareness about the importance of organ donation and transplantation within the PH community.

I am honored today to represent the hundreds of thousands of Americans who are fighting a courageous battle against a devastating disease. Pulmonary hypertension is a serious and often fatal condition where the blood pressure in the lungs rises to dangerously high levels. In PH patients, the walls of the arteries that take blood from the right side of the heart to the lungs thicken and constrict. As a result, the right side of the heart has to pump harder to move blood into the lungs, causing it to enlarge and ultimately fail.

PH can occur without a known cause or be secondary to other conditions such as: collagen vascular diseases (i.e., scleroderma and lupus), blood clots, HIV, sickle cell, or liver disease. PH impacts patients of all races, genders, and ages. Preliminary data from the REVEAL Registry suggests that the ratio of women to men who develop PH is 4:1. Patients develop symptoms that include shortness of breath, fatigue, chest pain, dizziness, and fainting.

Unfortunately, these symptoms are frequently misdiagnosed, leaving patients with the false impression that they have a minor pulmonary or cardiovascular condition. By the time many patients receive an accurate diagnosis, the disease has progressed to a late stage, making it impossible to receive a necessary heart or lung transplant. PH is chronic and incurable with a poor survival rate. Fortunately, new treatments are providing a significantly improved quality of life for patients with some managing the disorder for 20 years or longer.

In 1990, when three PH patients found each other with the help of the National Organization for Rare Diseases, and founded the Pulmonary Hypertension Association, there were less than 200 diagnosed cases of this disease. It was virtually unknown among the general population and not well known in the medical community. They soon realized that this was unacceptable, and formally established PHA, which is headquartered in Silver Spring, Maryland. I am pleased to report that we

are making good progress in our fight against this deadly disease. Nine medications for the treatment of PH have been approved by the FDA in the past 16 years.

Today, PHA includes:

- More than 20,000 members and supporters.
- A network of 230+ patient support groups and an active patient-to-patient telephone helpline.
- Three research programs that, through partnerships with the National Heart, Lung and Blood Institute, American Heart Association and the American Thoracic Society, have leveraged our donors' funds to commit more than \$10 million toward PH research as of 2011.
- Numerous electronic and print publications, including the first medical journal devoted to pulmonary hypertension—published quarterly and distributed to all cardiologists, pulmonologists, and rheumatologists in the United States.
- A state-of-the-art website (www.phassociation.org) dedicated to providing educational and support resources to patients, caregivers, and the public.
- A medical education website (www.phaonlineuniv.org), supported in part by the CDC, providing accredited medical education and resources to the medical community

FISCAL YEAR 2012 APPROPRIATIONS RECOMMENDATIONS

National Heart, Lung And Blood Institute

Less than two decades ago, a diagnosis of PH was essentially a death sentence, with only one approved treatment for the disease. Thanks to advancements made through the public and private sector, patients today are living longer and better lives with a choice of nine FDA approved medications. Recognizing that we have made tremendous progress, we are also mindful that we are a long way from where we want to be in (1) the management of PH as a treatable chronic disease, and (2) a cure.

We are grateful to the National Heart, Lung and Blood Institute for their leadership in advancing research on PH. Our Association is proud to jointly sponsor investigator training grants (K awards) with NHLBI aimed at supporting the next generation of pulmonary hypertension researchers.

Moreover, we were very pleased that NHLBI recently convened some of the community's leading scientists for a Working on Group on Lung Vascular Research. The panel produced recommendations that should guide pulmonary vascular disease research and treatment, including PH research, in coming years. Their recommendations, published in the American Journal of Respiratory and Critical Care Medicine in October, 2010 are as follows:

- Advance basic scientific research in lung vascular biology utilizing emerging technologies.
- Advance and coordinate basic and clinical knowledge of the pulmonary circulation-right heart axis through novel research efforts utilizing multidisciplinary teams.
- Define interactions between lung vascular components and circulating elements and systemic circulations by fostering novel collaborations.
- Encourage systems analysis to understand and define interactions between lung vascular genetics, epigenetics, metabolic pathways, and molecular signaling.
- Develop strategies using appropriate animal models to improve the understanding of the lung vasculature in health and in conditions that reflect human disease.
- Enhance translational research in lung vascular disease by comparing cellular and tissue abnormalities identified in animal models to those in human specimens.
- Improve lung vascular disease molecular and clinical phenotype coupling.
- Develop in vivo imaging techniques which assess structural changes in lung vasculature, metabolic shifts, functional cell responses and right ventricular function.
- Develop research consortia that advance basic, translational, and clinical studies, allow for multi-center epidemiological study feasibility, and support junior investigators' training in lung vascular biology and disease.

We encourage the Subcommittee to support the full implementation of these recommendations by the National Institutes of Health.

Mr. Chairman, expanding clinical research remains a top priority for patients, caregivers, and PH investigators. We are particularly interested in establishing a pulmonary hypertension research network. Such a network would link leading researchers around the United States, providing them with access to a wider pool of shared patient data. In addition, the network would provide researchers with the

opportunities to collaborate on studies and to strengthen the interconnections between basic and clinical science in the field of pulmonary hypertension research. Such a network is in the tradition of the NHLBI, which, to its credit and to the benefit of the American public, has supported numerous similar networks including the Acute Respiratory Distress Syndrome Network and the Idiopathic Pulmonary Fibrosis Clinical Research Network. We encourage the NHLBI to move forward with the establishment of a PH network in fiscal year 2012.

For fiscal year 2012, PHA joins with other voluntary patient and medical organizations in recommending an appropriation of \$35 billion for the National Institutes of Health. This level of funding will ensure continued expansion of research on rare diseases like pulmonary hypertension.

Centers For Disease Control And Prevention

Mr. Chairman, we are grateful to the subcommittee for providing past support of PHA's Pulmonary Hypertension Awareness Campaign. We know for a fact that Americans are dying due to a lack of awareness of PH, and a lack of understanding about the many new treatment options. This unfortunate reality is particularly true among minority and underserved populations. More needs to be done to educate both the general public and healthcare providers if we are to save lives.

To that end, PHA has utilized the funding provided through the CDC to: (1) launch a successful media outreach campaign focusing on both print and online outlets; (2) expand our support programs for previously underserved patient populations; and (3) establish PHA Online University, an interactive curriculum-based website for medical professionals that targets pulmonary hypertension experts, primary care physicians, specialists in pulmonology/cardiology/rheumatology, and allied health professionals. The site is continually updated with information on early diagnosis and appropriate treatment of pulmonary hypertension. It serves as a center point for discussion among PH-treating medical professionals and offers Continuing Medical Education and CEU credits through a series of online classes.

In fiscal year 2012, we encourage the subcommittee to establish a specific program at CDC to provide ongoing support for PH education and awareness activities. This would make a tremendous difference in the fight against this devastating disease.

"Gift Of Life" Donation Initiative at HRSA

PHA applauds the success of the Health Resources and Services Administration's "Gift of Life" Donation Initiative. This important program is working to increase organ donation rates across the country. Unfortunately, the only "treatment" option available to many late-stage PH patients is a lung, or heart and lung, transplantation. This grim reality is why PHA established "Bonnie's Gift Project."

"Bonnie's Gift" was started in memory of Bonnie Dukart, one of PHA's most active and respected leaders. Bonnie battled with PH for almost 20 years until her death in 2001 following a double lung transplant. Prior to her death, Bonnie expressed an interest in the development of a program within PHA related to transplant information and awareness.

PHA has had a very successful partnership with HRSA's "Gift of Life" Donation Program in recent years. Collectively, we have worked to increase organ donation rates and raise awareness about the need for PH patients to "early list" on transplantation waiting lists. For fiscal year 2012, PHA recommends an appropriation of \$26 million for this important program.

Social Security Disability

Finally Mr. Chairman, PHA would like to thank the subcommittee for its commitment to address the longstanding backlog of disability claims at the Social Security Administration. We greatly appreciate this investment as a growing number of our patients are applying for disability coverage. On a related note, the SSA recently convened an Institute of Medicine panel to recommend revisions to the disability criteria for cardiovascular diseases. The IOM worked closely with our medical experts to update the disability criteria for our patient population and we were pleased to receive their recommendations earlier this year. We encourage Congress to support this process moving forward.

PREPARED STATEMENT OF THE RESEARCH WORKING GROUP OF THE FEDERAL AIDS POLICY PARTNERSHIP

Chairman Harkin, Ranking Member Shelby and members of the Committee, thank you for the opportunity to provide testimony on the National Institutes of Health (NIH) budget overall and for AIDS research in fiscal year 2012. Tomorrow's

scientific and medical breakthroughs depend on your vision, leadership and commitment toward robust NIH funding over the next year. To this end, the Research Working Group (RWG) urges this Committee to support—at minimum—the President's NIH budget request and also recommends a funding target of \$35 billion in fiscal year 2012 to maintain the U.S.'s position as the world leader in medical research and innovation.

Investments in health research via NIH have paid enormous dividends in the health and well-being of people in the United States and around the world. NIH funded HIV and AIDS research has supported innovative basic science for better drug therapies, evidence-based behavioral and biomedical prevention interventions and vaccines which have saved and improved the lives of millions and holds great promise for significantly reducing HIV infection rates and providing more effective treatments for those living with HIV/AIDS in the coming decade.

Despite these advances, the number of new HIV/AIDS cases continues to rise in various populations in the United States and around the world. There are over 1 million HIV-infected people in the United States, the highest number in the epidemic's 30-year history; additionally over 56,000 Americans become newly infected every year. The evolving HIV epidemic in the United States disproportionately affects the poor, sexual and racial minorities and the most disenfranchised and stigmatized members of our communities. However, with proper funding coupled with the promotion of evidence based policies, 2012 will be a time of great scientific progress in prevention science, vaccines and finding a cure for HIV as well as addressing the co-morbid illnesses that affect patients with HIV such as viral hepatitis and tuberculosis. Further, as Washington, DC is set to host the International AIDS Conference in the summer of 2012, the gains in science made by NIH funded research programs will reflect our preeminence as the world's most powerful research enterprise fighting this deadly epidemic.

Major advances over the last 2 years in HIV prevention technologies—in particular with microbicides, HIV vaccines, circumcision, antiretroviral treatment as prevention and pre exposure prophylaxis using antiretrovirals (PrEP)—demonstrate that adequately resourced NIH programs can transform our lives. Federal support for AIDS research has also led to new treatments for other diseases, including cancer, heart disease, Alzheimer's, hepatitis, osteoporosis and a wide range of autoimmune disorders. Over the years, NIH has sponsored the evaluation of a host of vaccine candidates, some of which are advancing to efficacy trials. The recent successful iPrEx and HPTN 052 trials have shown the potential of antiretroviral drugs to prevent HIV infection. Moreover increased funding will support the future testing of new microbicides and therapeutics in the pipeline via the implementation of a newly restructured, cross-cutting HIV clinical trials network which translates NIH funded scientific innovation into critical quality of life gains for those most affected with HIV.

Increased funding for NIH in fiscal year 2012 makes good bipartisan economic sense, especially in shaky times. Robust funding for NIH overall will enable research universities to pursue scientific opportunity, advance public health, and create jobs and economic growth. In every State across the country, the NIH supports research at hospitals, universities, private enterprises and medical schools. This includes the creation of jobs that will be essential to future discovery. Sustained investment is also essential to train the next generation of scientists and prepare them to make tomorrow's HIV discoveries. NIH funding puts 350,000 scientists to work at research institutions across the country. According to NIH, each of its research grants creates or sustains six to eight jobs and NIH supported research grants and technology transfers have resulted in the creation of thousands of new independent private sector companies. Strong, sustained NIH funding is a critical national priority that will foster better health and economic revitalization.

Let's not jeopardize our future. Since 2003, funding for the NIH has failed to keep up with our existing research needs—damaging the success rate of approved grants and leaving very little money to fund promising new research. The real value of the increases prior to 2003 has been precipitously reduced because of the relatively higher inflation rate for the cost of research and development activities undertaken by NIH. According to the Biomedical Research and Development Price Index—which calculates how much the NIH budget must change each year to maintain purchasing power—between fiscal year 2003 and fiscal year 2011, the cost of NIH activities according to the BRDI will have increased by 32.8 percent. By comparison, the overall budget of the NIH increased by \$3.6 billion or 13.4 percent over fiscal year 2003. So in real terms, the NIH has already sustained budget decreases of close to 20 percent over the past 9 years due to inflation alone. As such, any further cuts to NIH will have the clear and devastating effects of undermining our Nation's leadership in health research and our scientists' ability to take advantage of the ex-

panding opportunities to advance healthcare. The race to find better treatments and a cure for cancer, heart disease, AIDS and other diseases, and for controlling global epidemics like AIDS, tuberculosis and malaria, all depend on a robust long term investment strategy for health research at NIH.

In conclusion, the RWG calls on Congress to continue the bipartisan Federal commitment toward combating HIV as well as other chronic and life threatening illnesses by increasing funding for NIH to \$35 billion in fiscal year 2012, including funds for transfer to the Global Fund for HIV/AIDS, Tuberculosis, and Malaria. A meaningful commitment toward stemming the epidemic and securing the well being of people with HIV cannot be met without prioritizing the research investment at NIH that will lead to tomorrow's lifesaving vaccines, treatments and cures. Thank you for the opportunity to provide these comments.

PREPARED STATEMENT OF RESEARCH!AMERICA

Thank you for the opportunity to submit testimony regarding fiscal year 2012 appropriations for the Subcommittee on Labor, Health, and Human Services, Education and Related Agencies. Research!America is the Nation's largest 501(c)(3) alliance working to make research to improve health a higher national priority. Research!America's member organizations together represent the voices of more than 125 million Americans. Our mission is grounded in strong and consistent expression by the American public for robust funding and policies in support of health research in the public and private sector. We use evidence-based advocacy to demonstrate the benefits of research that improves public health, productivity, longevity, and prosperity while solidifying America's standing as the world's engine of innovation.

Our remarks will focus on funding for the National Institutes of Health (NIH), the Centers for Disease Control and Prevention (CDC), the Food and Drug Administration (FDA) and the Agency for Healthcare Research and Quality (AHRQ)—agencies that play a pivotal role in advancing the health of Americans and fueling economic growth across our Nation. In addition to these agencies, Research!America also advocates for the National Science Foundation (NSF), which fosters basic science and discovery that also impacts the health of Americans.

Research!America appreciates the subcommittee's past support for robust research funding conducted and supported by NIH, CDC, FDA, and AHRQ. Health research is in our Nation's best short- and long-term interests. Investing in research saves lives, saves dollars, produces jobs across multiple sectors of our economy, and positions our Nation for sustained global competitiveness.

The Nation is facing a debt crisis. Our debt burden will increase if we underfund agencies that drive economic growth and the private sector innovation critical to our global competitiveness. Robust support for health research agencies is critical for solving the debt crisis, reigning in the cost of medical care, and getting the economy back on track.

NIH, CDC, AHRQ and FDA each contribute in multifaceted ways to improved health and the economic growth our Nation.

- Research funded by the National Institutes of Health at research institutions across the country provides the groundwork for new product development in the private sector, which creates jobs and pumps dollars into local economies.
- The Centers of Disease Control and Prevention engage in epidemiological and public health research that stems deadly and costly pandemics, bolsters our Nation's defenses against bioterrorism, and addresses public health threats like drug-resistant infections that increase hospital costs and threaten lives.
- Research supported by the Agency for Healthcare Research and Quality improves the efficiency and quality of healthcare in this country by reducing duplication and waste and improving healthcare outcomes;
- By ensuring the safety and efficacy of new medicines and medical devices, The Food and Drug Administration plays a pivotal role in translating health research into improved treatments for patients.

As polling commissioned by Research!America clearly demonstrates, the American public strongly supports robust investment in health and medical research. A recent poll that surveyed a mix of self-described conservatives (32 percent), liberals (32 percent) and moderates (36 percent) found that, as we emerge from the recession:

- 78 percent of Americans think Federal funding for health research is important for job creation and the economy;
- 61 percent say accelerating our Nation's investment in research to improve health is a priority;
- 76 percent think global health R&D is important to the U.S. economy;

- 84 percent think it is important that the Government plays a role in research for prevention and wellness; and
- 53 percent of Americans think that spending cuts are necessary, but the United States must invest strategically to improve the health of the economy.

The poll also confirms that Americans value public/private collaboration in order to rapidly build on discoveries made in federally funded labs to bring new drugs and devices to market. Some 84 percent of Americans think it is important to invest in regulatory science, an increasingly important area of focus at FDA and NIH, to make the drug and device development process more efficient for businesses and safer for patients.

Additional findings from Research!America polling include:

- 91 percent of Americans think R&D is important to their State's economy;
- 83 percent agree that basic scientific research should be funded by the Federal government;
- 66 percent think research to improve health is part of the solution to rising healthcare costs.

The American public knows that research not only saves lives, but money. Disease and disability pose a major economic threat to our Nation, as the aging of our population and rising obesity rates increase the prevalence of heart disease, cancer, stroke, diabetes, Parkinson's disease, Alzheimer's disease and other major illnesses. It is estimated that chronic disease alone costs the United States \$1.7 trillion each year.¹ Research conducted by both the public and private sectors is a potent weapon against rising healthcare costs. For example:

- An NIH-sponsored clinical trial showed treatment with aspirin could reduce stroke in Atrial Fibrillation (AF) victims by 80 percent, resulting in a 10-year net benefit of \$1.27 billion.²
- A breast cancer diagnostic test developed by a private company using data from the publicly funded human genome project saves an estimated \$2,000 per patient by reducing the number of women who are prescribed chemotherapy.³
- A recent NIH-funded study shows that vaccinating healthy, employed adults (ages 18 to 50) against the flu saves as much as \$31 per person.⁴

U.S. research leading to the control and eradication of global illnesses can dramatically increase global productivity, while helping to protect Americans. In addition to benefiting our troops abroad, U.S. research focused on global diseases is actually an investment in the health of Americans. International travel means that it is not a matter of if, but when, deadly global threats, such as multiple-drug resistant tuberculosis reach the United States. Every year, 60 million Americans travel to other countries and 50 million people from abroad travel to the United States.⁵

In an interconnected world, U.S. global research helps grow our economy and saves lives at home and abroad.

Both the NIH and the CDC work closely with other agencies, like the U.S. Agency for International Development (USAID) to support the development of new biomedical, diagnostic, and other global health-related technologies. Through public private partnerships (PPP), including product development partnerships (PDP), these agencies leverage expertise from academia, private sector, and others to create new tools to combat neglected diseases throughout the world. This innovative collaborative PDP model has resulted in 12 novel products that could prove transformative for global health. We urge the committee to provide continued and robust support for these programs that touch every corner of our world, save lives, and strengthen the U.S. economy.

Whether the goal is to save lives, bend the cost curve by progressively reducing the cost of treating chronic and life-threatening health conditions, or promote the kind of innovation that positions our Nation for global economic leadership now and in the future, ample funding for NIH, CDC, FDA, and AHRQ is a cost-effective investment. Research!America appreciates the difficult task facing the subcommittee and urges that you recognize the return on investment that these four Federal agencies bring to our country. Investing in these agencies is the right, and smart, choice.

¹ Partnership to Fight Chronic Disease, Almanac of Chronic Disease, 2009.

² Johnston SC, Rootenberg JD, Katrak S, et. al. Effect of a US NIH programme of clinical trials on public health and costs. *The Lancet* 2006;367:1319–1327.

³ Lyman, G.H. et al. Impact of a 21-gene RT-PCR assay on treatment decisions in early-stage breast cancer. *Cancer*. 2007; 109:1011–1118.

⁴ Lee, Patrick Y. "Economic Analysis Of Influenza Vaccination And Antiviral Treatment For Healthy Working Adults." *Annals of Internal Medicine* 137 (2002): 225–31.

⁵ ITA (International Trade Administration), Office of Travel and Tourism Industries, "Total International Travelers Volume to and from the U.S. 1995–2005," available online at http://tinnet.ita.doc.gov/outreachpages/inbound.total_intl_travel_volume_1995-2005.html.

PREPARED STATEMENT OF ROTARY INTERNATIONAL

Chairman Harkin, members of the Subcommittee, Rotary International appreciates this opportunity to submit testimony to the in support of the polio eradication activities of the U.S. Centers for Disease Control and Prevention (CDC). The Global Polio Eradication Initiative is an unprecedented model of cooperation among national governments, civil society and U.N. agencies to work together to reach the most vulnerable through a safe, cost-effective public health intervention, and one which is increasingly being combined with opportunistic, complementary interventions such as the distribution of life-saving vitamin A drops, oral rehydration therapy, zinc supplements, and even something as simple as the distribution of soap. The goal of a polio free world is within our grasp because polio eradication strategies work even in the most challenging environments and circumstances.

PROGRESS IN THE GLOBAL PROGRAM TO ERADICATE POLIO

Thanks to this committee's leadership in appropriating funds, progress toward a polio-free world continues.

- Only 4 countries (Nigeria, India, Pakistan and Afghanistan) are polio-endemic—the lowest number in history.
- The number of polio cases has fallen from an estimated 350,000 in 1988 to less than 1300 in 2010—a more than 99 percent decline in reported cases.
- As of April 21, 2011, Uttar Pradesh (UP) in India celebrated 1 year without reporting a single case of polio. The state has traditionally been a major exporter of virus to other parts of India and the world, and has been described as one of the most difficult places to eradicate polio.
- The number of polio cases in the polio endemic countries of India and Nigeria declined by more than 90 percent in 2010 as compared to 2009. As of 2011, India has reported only 1 case; Nigeria—5 cases.
- Incidence of type 3 polio, which accounted for 70 percent of all polio cases in 2009, decreased significantly in 2010 accounting for only 8 percent of all cases.
- Bivalent oral polio vaccine, which was introduced at the end of 2009, has proven to effectively target both of the remaining strains of polio, and has been a major factor in the progress made in 2010.
- A shortfall in the funding needed for polio eradication activities in polio affected and at-risk countries continues to pose a serious threat the achievement of a polio free world.

In summary, significant operational progress was made in 2010 despite funding challenges and outbreaks which, will continue to threaten polio free countries until polio eradication is achieved. Rotary, as a spearheading partner of the GPEI, will continue to pursue aggressive progress as outlined in the Strategic Plan for 2010–12 which has already demonstrated results in terms of reducing the number of cases in 2010 and into 2011.

The ongoing support of donor countries is essential to assure the necessary human and financial resources are made available to polio-endemic countries to take advantage of the window of opportunity to forever rid the world of polio. Access to children is needed, particularly in conflict-affected areas such as Afghanistan and its shared border with Pakistan. Polio-free countries must maintain high levels of routine polio immunization and surveillance. The continued leadership of the United States is essential to ensure we meet these challenges.

THE ROLE OF ROTARY INTERNATIONAL

Rotary International, a global association of more than 32,000 Rotary clubs in more than 170 countries with a membership of over 1.2 million business and professional leaders (more than 365,000 of which are in the United States), has been committed to battling polio since 1985. Rotary International has contributed more than US\$1 billion toward a polio free world—representing the largest contribution by an international service organization to a public health initiative ever. Rotary also leads the United States Coalition for the Eradication of Polio, a group of committed child health advocates that includes the March of Dimes Foundation, the American Academy of Pediatrics, the Task Force for Global Health, the United Nations Foundation, and the U.S. Fund for UNICEF. These organizations join us in thanking you for your staunch support of the Polio Eradication Initiative.

THE ROLE OF THE U.S. CENTERS FOR DISEASE CONTROL AND PREVENTION (CDC)

Rotary commends CDC for its leadership in the global polio eradication effort, and greatly appreciates the Subcommittee's support of CDC's polio eradication activities. The investment in this global effort has helped to make the United States the leader

among donor nations in the drive to eradicate this crippling disease. Due to congressional support, in fiscal year 2010 and fiscal year 2011 CDC was able to:

- Support the international assignment of more than 358 long- and short-term epidemiologists, virologists, and technical officers to assist the World Health Organization and polio-endemic countries to implement polio eradication strategies while on temporary duty travel from Atlanta, and 31 technical staff on direct 2-year assignments to WHO and UNICEF to assist polio-endemic and polio-re-infected countries.
- Perform the lead technical monitoring role for the Global Polio Eradication Initiative (GPEI) Strategic Plan 2010–2012 released in May 2010. On a quarterly basis, beginning in Q4, 2010, CDC provided a detailed epidemiologic report and risk assessment on the progress toward achieving the goals outlined in the Strategic Plan to the Independent Monitoring Board (IMB) for policy and decision-making.
- Provide \$53.4 million in fiscal year 2010 to UNICEF for approximately 292 million doses of polio vaccine and \$7.3 million for operational costs for NIDs in all polio-endemic countries and other high-risk countries in Asia, the Middle East and Africa. Most of these NIDs would not take place without the assurance of CDC's support.
- Collaborate with WHO, UNICEF, Rotary International, U.N. Foundation and the Bill and Melinda Gates Foundation to facilitate World Bank financing through its buy-down mechanism for the purchase of OPV. In 2010, this mechanism provided \$14.1 million to Nigeria and \$37.3 million to Pakistan. For 2011, Nigeria has been approved for \$60 million, 1-year credit and Pakistan is eligible for a \$41 million, 1-year credit.
- Provide \$30.9 million in fiscal year 2010 to WHO for surveillance, technical staff and NIDs' operational costs, primarily in Africa. As successful NIDs take place, surveillance is critical to determine where polio cases continue to occur. Effective surveillance can save resources by eliminating the need for extensive immunization campaigns if it is determined that polio circulation is limited to a specific locale.
- Train virologists from around the world in advanced poliovirus research and public health laboratory support. CDC's Atlanta laboratories are a global reference center and training facility.
- Provide, as the leading specialize polio reference lab in the world, the largest volume of operational (poliovirus isolation) and technologically sophisticated (genetic sequencing of polio viruses) lab support to the 145 laboratories of the global polio laboratory network.
- Provide scientific and technical expertise to WHO on research issues regarding: (1) laboratory containment of wild poliovirus stocks following polio eradication, and (2) when and how to stop or modify polio vaccination following global certification of polio eradication.
- Provide critical support for post-polio-eradication planning through research, new product development, strategy formulation and policy development.
- Train and deploy public health professionals to improve AFP surveillance and to help plan, implement, and evaluate vaccination campaigns, communications, etc. through CDC's Stop Transmission of Polio (STOP) program. Since 1999, more than 1,000 STOP team members have participated in 3-month assignments in 60 countries, providing 262 person-years of support at the national and State levels. In 2010, the STOP program deployed 185 professionals to 69 countries.
- Launch a customized N (national)-STOP initiative in March 2011 in collaboration with the Pakistan Ministry of Health, WHO and the USAID Mission in Islamabad. Sixteen national epidemiologists from CDC's Field Epidemiology Training Program (FETP) were trained and deployed to the highest risk districts for circulation of wild polio virus in an effort to help improve the quality of disease surveillance and immunization activities there and to strengthen routine immunization systems.
- Deploy E (enhanced)-STOP initiative teams to Nigeria, S. Sudan, Angola, Chad, and DRC. Those serving in E-STOP are assigned to support efforts in strategic areas, are more experienced, and serve for a longer durations. As part of E-STOP in 2010, 28 professionals were deployed to Nigeria, 35 to South Sudan, 7 to Angola, 5 to Chad, and 5 to DRC. This initiative was facilitated by an expanding partnership with the Organization of Islamic Conference (OIC) facilitating outreach to Muslim states and the Pan American Health Organization facilitating Brazilian and Southern Cone support for Angola. With available funding, CDC plans to expand the number of participants in E-STOP in 2011.

—Support global polio eradication by participating in technical advisory groups, EPI manager and other key meetings. The CDC also published 14 updates on progress toward polio eradication in the Morbidity and Mortality Weekly Report (MMWR) and other peer-reviewed journals.

FISCAL YEAR 2012 BUDGET REQUEST

For fiscal year 2012, we respectfully request that this subcommittee include \$112 million for the targeted polio eradication efforts of the Centers for Disease Control and Prevention, the same level included in the President's fiscal year 2012 request. The funds we are seeking will allow CDC to continue intense supplementary immunization activities in Asia and to improve the quality of immunization campaigns in Africa to interrupt transmission of polio in these regions as quickly as possible. These funds will also help maintain certification standard surveillance. This will ensure that we protect the substantial investment we have made to protect the children of the world from this crippling disease by supporting the necessary eradication activities to eliminate polio in its final strongholds—in South Asia and sub-Saharan Africa.

The United States' commitment to polio eradication has stimulated other countries to increase their support. Other countries that have followed America's lead and made special grants for the global Polio Eradication Initiative include the United Kingdom (\$900.03 million), Japan (\$418.65 million), Germany (\$390.94 million), and Canada (\$289.53 million). Since 2002, the members of the G8 have committed to provide sufficient resources to eradicate polio. G8 member states, many of which were already leading donors to the Polio Eradication Initiative, have encouraged other donors to provide support, and have emphasized the importance of polio eradication when meeting with leaders of polio-endemic countries. As a result, the base of donor nations that have contributed to the Global Polio Eradication Initiative has expanded to include Spain, Sweden, Saudi Arabia, and even contributions from United Arab Emirates, Kuwait, Hungary, and Turkey.

Endemic nations are also providing funds to support polio eradication activities. It is noteworthy that India has provided US\$692 million in funding for polio eradication activities there since 2003 and Nigeria provided approximately US\$61.75 million, and Pakistan has provided US\$50 million.

BENEFITS OF POLIO ERADICATION

Since 1988, over 5 million people who would otherwise have been paralyzed will be walking because they have been immunized against polio. Tens of thousands of public health workers have been trained to manage massive immunization programs and investigate cases of acute flaccid paralysis. Cold chain, transport and communications systems for immunization have been strengthened. The global network of 145 laboratories and trained personnel established for polio eradication also tracks measles, rubella, yellow fever, meningitis, and other deadly infectious diseases and will do so long after polio is eradicated. NIDs for polio have also been used to distribute essential vitamin A, thereby saving the lives of over 1.25 million children since 1988.

A study published in the November 2010 issue of the journal *Vaccine* estimates that the global polio eradication initiative to eradicate polio could provide net benefits of at least \$40–50 billion if transmission of wild polio viruses is stopped within the next 5 years. Polio eradication is a cost-effective public health investment, as its benefits accrue forever. On the other hand, more than 10 million children will be paralyzed in the next 40 years if the world fails to capitalize on the more than \$8 billion already invested in eradication. Success will ensure that the significant investment made by the United States, Rotary International, and many other countries and entities, is protected in perpetuity.

PREPARED STATEMENT OF THE RYAN WHITE MEDICAL PROVIDERS COALITION

Introduction

I am James Raper, a nurse practitioner and Director of the 1917 HIV/AIDS Outpatient Clinic at the University of Alabama at Birmingham. I am submitting written testimony on behalf of the Ryan White Medical Providers Coalition.

Thank you for the opportunity to discuss the important HIV/AIDS care conducted at Ryan White Part C funded programs nationwide. Specifically, the Ryan White Medical Provider Coalition, the HIV Medicine Association, the CAEAR Coalition, and the American Academy of HIV Medicine estimate that approximately \$407 million is needed to provide the standard of care for all Part C program patients. (This

estimate is based on the current cost of care and the number of patients that Part C clinics serve.) Because these are exceptionally challenging economic times, we request \$272 million for Ryan White Part C programs in fiscal year 2012, the amount that Congress authorized for Part C programs in its 2009 reauthorization of the Ryan White Program.

The Ryan White Medical Providers Coalition was formed in 2006 to be a voice for medical providers across the Nation delivering quality care to their patients through Part C of the Ryan White program. We represent every kind of program, from small and rural to large urban sites in every region in the country. We speak for those who often cannot speak for themselves and we advocate for a full range of primary care services for these patients. Sufficient funding for Part C is essential to providing appropriate care for individuals living with HIV/AIDS.

Part C of the Ryan White Program funds comprehensive Early Intervention Services (EIS) for HIV care and treatment, that are directly responsible for the dramatic decreases in AIDS-related mortality and morbidity over the last decade. The Centers for Disease Control and Prevention estimate that there are more than 1.1 million persons living with HIV/AIDS, and approximately 240,000, or almost 1 in 4, of these individuals received services from Part C medical providers—a dramatic 30 percent increase in patients in less than 10 years.

The Cost of Care Is Reasonable; The Reimbursement for Care Isn't

On average it costs \$3,501 per person per year to provide the comprehensive outpatient care and treatment available at Part C funded programs (excluding medication costs), including lab work, STD/TB/Hepatitis screening, ob/gyn care, dental care, mental health and substance abuse treatment, and case management. Part C funding covers only a small percentage of the total cost of this comprehensive care, with some programs receiving \$450 (12 percent of the total cost) or less per patient per year to cover the cost of care.

Part C Programs Save Both Lives and Money

Investing in Part C services improves lives and saves money. In the United States, nearly 50 percent of persons living with HIV/AIDS who are aware of their status are not in continuing care. Early and reliable access to HIV care and treatment both helps patients with HIV live relatively healthy and productive lives and is more cost effective. One study from my Part C Clinic at the University of Alabama at Birmingham found that patients treated at the later stages of HIV disease required 2.6 times more healthcare dollars than those receiving earlier treatment meeting Federal HIV treatment guidelines.

Patient Loads Are Increasing at an Unsustainable Rate

Patient loads have been increasing at Part C clinics nationwide, despite the fact that there has not been significant new Federal funding, and in most cases, State and/or local funding has been cut. A steady increase in patients has occurred on account of higher diagnosis rates and declining insurance coverage resulting in part from the economic downturn. The CDC reports that the number of HIV/AIDS cases increased by 15 percent from 2004 to 2007 in 34 States.¹

For example, at a clinic in Greensboro, North Carolina, the number of patients has more than doubled from 321 patients in 2002 to more than 800 in 2009. The clinic continues to deliver care in the same space with the same staffing as in 2002 despite the 250 percent increase in patients. In Sonoma County, California, funding became so scarce that the Part C clinic there closed its doors, and had to patch together new medical homes in other locations for 350 patients. In New York, when St. Vincent's Hospital in New York City closed, including the HIV/AIDS clinic, a Part C clinic at St. Luke's-Roosevelt Hospital had to absorb almost the entire St. Vincent's clinic, approximately 1,000 patients, over the course of just a few days.

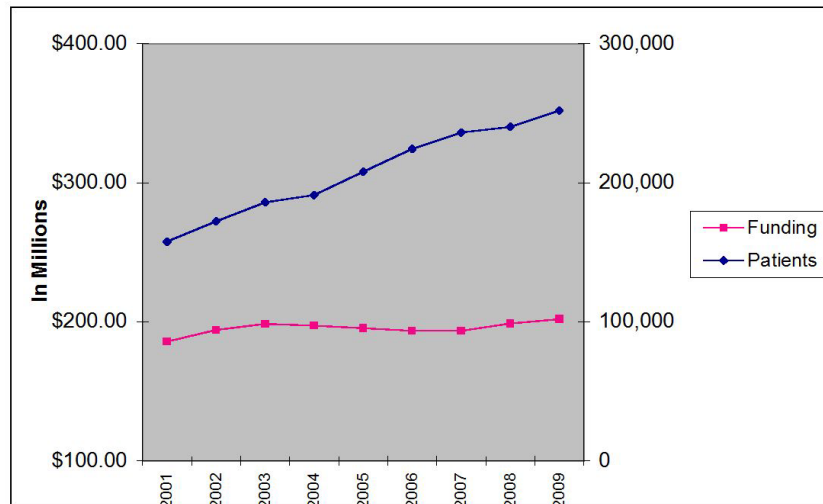
Our patients struggle in times of plenty, and during this economic downturn they have relied on Part C programs more than ever. While these programs have been under-funded for years, State and local economic pressures are creating a crisis in our communities. Clinics are discontinuing primary care and other critical medical services, such as laboratory monitoring; suffering eviction from their clinic locations; operating only 4 days per week; and laying off staff just to get by. Years of nearly flat funding combined with large increases in the patient population and the recent economic crisis are negatively impacting the ability of Part C providers to serve their patients.

¹Centers for Disease Control and Prevention. HIV/AIDS Surveillance Report, 2007. Vol. 19. U.S. Department of Health and Human Services, Centers for Disease Control and Prevention; 2009:5. www.cdc.gov/hiv/topics/surveillance/resources/reports/.

The following graph demonstrates the growing disparity between funding for Part C and the increasing patient population. I refer to this gap between funding and patients as the “Triangle of Misery” because it represents both the thousands of patients who deserve more than we can offer and the Part C programs nationwide that are struggling to serve them with shrinking resources.

THE TRIANGLE OF MISERY

2001 to 2009: Part C Patients Increased by 59%, While Funding Only Increased by 8.6%



Conclusion

These are challenging economic times, and we recognize the severe fiscal constraints Congress faces in allocating limited Federal dollars. The significant financial and patient pressures that we face in our clinics at home propel us to make this funding request for fiscal year 2012 funding of Ryan White Part C programs. This funding would help to support medical providers nationwide in delivering appropriate and effective HIV/AIDS care to their patients. As the survey below of Part C providers nationwide shows, this Federal support is urgently needed.

Thank you for your time and consideration of our request. If you have any questions, please do not hesitate to contact me at the 1917 HIV/AIDS Outpatient Clinic, University of Alabama at Birmingham, Birmingham, Alabama 35294-2050, e-mail at jimraper@uab.edu.

RWMPC SURVEY: BUDGETARY CONSTRAINTS CONTINUE TO DRIVE CUTBACKS IN HIV CARE

In January 2011, the Ryan White Medical Providers Coalition, which represents Ryan White Part C programs nationwide that provide comprehensive HIV medical care and treatment, asked members to indicate their top three concerns as well as their frontline experiences providing HIV care and treatment in the current, constrained economic environment. The results of the brief survey included:

- The top three concerns (in order of importance):
 - Funding cuts/shortfalls
 - Sustaining the Ryan White Program and Part C programs and preparing for health reform
 - Clinic management issues, including:
 - HIV medical workforce recruitment and retention
 - Access to medications for patients (including the amount of work that clinics are doing to secure this access now that the ADAP crisis has worsened)
 - Increasing patient loads and the fact that clinics are reaching the limits of what they can do within their current financial and workforce resources.
- For those who are worried about funding cuts and shortfalls, 57 percent are worried about cuts to Federal funds.

- More than 56 percent of respondents have made cuts or changes to their programs because of funding cuts or shortfalls (both state and Federal).
- The types of cuts or changes that have been made include:
 - More than 32 percent of clinics have either reduced or cut the services they provide.
 - 21.5 percent have either frozen their hiring or laid off staff
 - 13.5 percent have reduced coverage for lab monitoring

These survey results indicate the need to support and increase the investment in Part C programs, a valuable, effective and cost efficient resource that provides medical homes to tens of thousands of persons with HIV nationwide. Unless Part C programs receive additional funding, more services and infrastructure will be lost during this critical time period before the implementation of healthcare reform in 2014. Loss of such resources and infrastructure would reduce the availability of quality HIV care and treatment at just the time when the National HIV/AIDS Strategy is hoping to increase access to these life-saving services.

PREPARED STATEMENT OF THE SCLERODERMA FOUNDATION
FISCAL YEAR 2012 APPROPRIATIONS RECOMMENDATIONS

Funding for the National Institutes of Health (NIH) at a level of \$35 million.

An increase for the National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS) concurrent with the overall increase to NIH.

Committee recommendation encouraging the Centers for Disease Control and Prevention to partner with the Scleroderma Foundation in promoting increased awareness of scleroderma among the general public and healthcare providers.

Mr. Chairman, I am Cynthia Cervantes, I am 12 and in the ninth grade. I live in Southern California and in October 2006 I was diagnosed with scleroderma. Scleroderma means “hard skin” which is literally what scleroderma does and, in my case, also causes my internal organs to stiffen and contract. This is called diffuse scleroderma. It is a relatively rare disorder effecting only about 300,000 Americans.

About 2 years ago I began to experience sudden episodes of weakness, my body would ache and my vision was worsening, some days it was so bad I could barely get myself out of bed. I was taken to see a doctor after my feet became so swollen that calcium began to ooze out. It took the doctors (period of time) to figure out exactly what was wrong with me, because of how rare scleroderma is.

There is no known cause for scleroderma, which affects three times as many women as men. Generally, women are diagnosed between the ages of 25 and 55, but some kids, like me, are affected earlier in life. There is no cure for scleroderma, but it is often treated with skin softening agents, anti-inflammatory medication, and exposure to heat. Sometimes a feeding tube must be used with a scleroderma patient because their internal organs contract to a point where they have extreme difficulty digesting food.

The Scleroderma Foundation has been very helpful to me and my family. They have provided us with materials to educate my teachers and others about my disease. Also, the support groups the foundation helps organize are very helpful because they help show me that I can live a normal, healthy life, and how to approach those who are curious about why I wear gloves, even in hot weather. It really means a lot to me to be able to interact with other people in the same situation as me because it helps me feel less alone.

Mr. Chairman, because the causes of scleroderma are currently unknown and the disease is so rare, and we have a great deal to learn about it in order to be able to effectively treat it. I would like to ask you to please significantly increase funding for the National Institute of Health so treatments can be found for other people like me who suffer from scleroderma. It would also be helpful to start a program at the Centers for Disease Control and Prevention to educate the public and physicians about scleroderma.

OVERVIEW OF THE SCLERODERMA FOUNDATION

The Scleroderma Foundation is a nonprofit organization based in Danvers, Massachusetts with a three-fold mission: support, education, and research. The Foundation provides support for people living with scleroderma and their families through programs such as peer counseling, doctor referrals, and educational information, along with a toll-free telephone helpline for patients.

The Foundation also provides education about the disease to patients, families, the medical community, and the general public through a variety of awareness programs at both the local and national levels. Over \$1 million in peer-reviewed re-

search grants are awarded annually to institutes and universities to stimulate progress in the search for a cause and cure for scleroderma.

WHO GETS SCLERODERMA?

There are many clues that define the susceptibility to develop scleroderma. A genetic basis for the disease has been suggested by the fact that it is more common among patients whose family members have other autoimmune diseases (such as lupus). In rare cases, scleroderma runs in families, although for the vast majority of patients there is no other family member affected. Some Native Americans and African Americans suffer a more severe form of the disease. Caucasians. Women between the ages of 25–55 are more likely to develop scleroderma.

CAUSES OF SCLERODERMA

The cause of scleroderma is unknown. However, we do understand a great deal about the biological processes involved. In localized scleroderma, the underlying problem is the overproduction of collagen (scar tissue) in the involved areas of skin. In systemic sclerosis, there are three processes at work: blood vessel abnormalities, fibrosis (which is overproduction of collagen) and immune system dysfunction, or autoimmunity.

RESEARCH

Unfortunately, support for scleroderma research at the National Institutes of Health over the past several years has been flat funded at \$19 million since fiscal year 2009, and is again estimated at \$19 million for fiscal year 2012. This absence of increase is extremely frustrating to our patients who recognize biomedical research as their best hope for a better quality of life. It is also of great concern to our researchers who have promising ideas they would like to explore if resources were available.

TYPES OF SCLERODERMA

There are two main forms of scleroderma: systemic (systemic sclerosis, SSc) that usually affects the internal organs or internal systems of the body as well as the skin, and localized that affects a local area of skin either in patches (morphea) or in a line down an arm or leg (linear scleroderma), or as a line down the forehead (scleroderma en coup de sabre). It is very unusual for localized scleroderma to develop into the systemic form.

Systemic Sclerosis (SSc)

There are two major types of systemic sclerosis or SSc: limited cutaneous SSc and diffuse cutaneous SSc. In limited SSc, skin thickening only involves the hands and forearms, lower legs and feet. In diffuse cutaneous disease, the hands, forearms, the upper arms, thighs, or trunk are affected.

People with the diffuse form of SSc are at risk of developing pulmonary fibrosis (scar tissue in the lungs that interferes with breathing, also called interstitial lung disease), kidney disease, and bowel disease. The risk of extensive gut involvement, with slowing of the movement or motility of the stomach and bowel, is higher in those with diffuse rather than limited SSc. Symptoms include feeling bloated after eating, diarrhea or alternating diarrhea and constipation.

Pulmonary Hypertension (PH) is high blood pressure in the blood vessels of the lungs. It is totally independent of the usual blood pressure that is taken in the arm. This tends to develop in patients with limited SSc after several years of disease. The most common symptom is shortness of breath on exertion. However, several tests need to be done to determine if PH is the real culprit. There are now many medications to treat PH.

Localized Scleroderma

Morphea

Morphea consists of patches of thickened skin that can vary from half an inch to 6 inches or more in diameter. The patches can be lighter or darker than the surrounding skin and thus tend to stand out. Morphea, as well as the other forms of localized scleroderma, does not affect internal organs.

Linear scleroderma

Linear scleroderma consists of a line of thickened skin down an arm or leg on one side. The fatty layer under the skin can be lost, so the affected limb is thinner than

the other one. In growing children, the affected arm or leg can be shorter than the other.

Scleroderma en coup de sabre

Scleroderma en coup de sabre is a form of linear scleroderma in which the line of skin thickening occurs on the forehead or elsewhere on the face. In growing children, both linear scleroderma and en coup de sabre can result in distortion of the growing limb or lack of symmetry of both sides of the face.

PREPARED STATEMENT OF SENIOR SERVICE AMERICA, INC.

We urge the subcommittee to restore funding for the Senior Community Service Employment Program (SCSEP), currently administered by the Department of Labor, to no less than \$600 million for fiscal year 2012. would return funding for this proven and unique Federal employment and training program to pre-ARRA levels.

SCSEP is the only Federal program targeted at assisting low income workers over the age of 55 either regain employment or provide minimum wage employment through community service in communities across the Nation. A restoration of funding for SCSEP to \$600 million would provide community service employment to an additional 24,000 unemployed and low-income older workers and at least 7 million lost staffing hours in participants' community service to local government agencies and nonprofit organizations meeting basic human needs.

We estimate that the public return on investment is more than double its appropriations level. The value of the community service by SCSEP participants would exceed \$900 million. In addition to the value of the this service, SCSEP produces savings to the Federal Government by helping many thousands of vulnerable older adults to avoid becoming totally dependent on government transfer payments, including Medicaid, Supplemental Security Income, and early receipt of Social Security benefits.

SCSEP's severe cut in fiscal year 2011 will have devastating impact on older workers and communities.—Restoring funding in fiscal year 2012 would lessen the impact of the 45 percent reduction in SCSEP as a result of the fiscal year 2011 year-long Continuing Resolution. The cut of \$375 million from fiscal year 2010 is larger than the WIA core funding cut. As a result, during the year starting July 1, 2011, nearly 50,000 fewer jobless older adults will be employed and almost 35 million staff hours will be lost by over 30,000 local agencies and programs throughout the 50 States. Using tables from the Independent Sector, the value of these lost SCSEP community service hours exceeds \$740 million.

SCSEP currently supports a wide range of community services and local government programs. For example, in 2011 over 1,100 public libraries (at least one in every State, most in rural areas) employed at least one SCSEP participant in a variety of library-related assignments. About one-fourth of all SCSEP community service hours are performed in service to other older adults, such as senior centers, nutrition, Meals on Wheels, and adult day care centers.

SCSEP is a unique Federal workforce development program.—According to a January 2011 GAO report on multiple employment and training programs, SCSEP is one of only three Federal workforce development programs that do not overlap with any other program. Since 1998, it is the only Federal program targeted to assist older adults return to the workforce and serves almost twice the number of adults 55 and over who receive training under WIA. Previous research by GAO and others have documented that WIA has consistently underserved older jobseekers.

Older adults, especially those eligible for SCSEP, continue to suffer in the current economy. Older workers have been described as the "new unemployables" in a recent report by Rutgers University. The current jobless rate for all older workers continues to be lower than the rate for all workers, but in 2010 the unemployment rate of older adults 55–74 years of age eligible for SCSEP was 23 percent, more than three times the national average for all adult workers. Among displaced workers 55 and older, the reemployment rate was only 38 percent, the lowest of any age group, with those from lower income households and with less than a college education faring the worst. Finally, the average duration of unemployment among adults 55 and over continued to increase in April 2011 to 53.6 weeks, with more than half of all older jobseekers out of work for 27 or more weeks, also an increase from the prior month. (More information is available from AARP and Senior Service America websites.)

The job market is not likely to improve significantly for most of these low-income and disadvantaged older job seekers in the foreseeable future. Too many will remain out of work and be forced to sustain themselves by becoming totally reliant on gov-

ernment transfers such as Medicaid, Supplemental Security Income, and early receipt of Social Security income benefits. Many will be highly unlikely to return to the labor force. Restoring SCSEP appropriations to pre-ARRA levels is a wise investment in a program of demonstrated effectiveness operated by a network of proven performers.

DOL's SCSEP grantee network consistently achieves its performance measures.—According to official statistics, in PY2009 the aggregate performance of the 18 national grantees and 56 State and territorial grantees achieved 98 percent or more of each of the common performance measures established for the program by DOL. For example, the grantee network achieved a 46.2 percent Entered Employment Rate (compared to the goal of 47 percent established by DOL); 70 percent Retention (68 percent goal); and \$6,900 6 month earnings (\$6,229 goal). For comparison, the Entered Employment Rate achieved was 48.1 percent in PY2008 and 52.4 percent in PY2007.

In addition, ratings by SCSEP participants and participating host agencies using the American Customer Satisfaction Index have been consistently higher for SCSEP than for WIA. In PY2009, participants gave SCSEP an ACSI score of 82.7 and host agencies gave a score of 81.3. Additional information from these independent national surveys:

SCSEP Participants (number of respondents=24,358)

ACSI score of 82.7 (about the same as prior year's score)

Nearly 92 percent of respondents reported that, compared to the time before they entered SCSEP, their physical health is the same or better, 73 percent reported that their outlook on life is a little more positive or much more positive.

Participants were in moderate to strong agreement (7.9 on a scale of 1 to 10) with the statement that their community service wages have made a substantial improvement in their quality of life.

SCSEP Host Agencies (number of respondents=10,567)

ACSI score of 81.3 (nearly identical to prior year's score)

75 percent indicated that participation in SCSEP increased their ability to provide services to the community either "somewhat" or "significantly."

The impact of the fiscal year 2011 cuts to SCSEP will be felt in every State. For example:

Impact on Iowa: Loss of nearly \$5 million in SCSEP funding and over \$7 million in services.

During fiscal year 2010, about 490 local programs in 153 Iowa towns and cities hosted at least one SCSEP participant, including: 171 local and State government agencies; 71 programs serving older adults, including at least 20 senior centers; 36 schools and post-secondary institutions; 31 workforce development offices; 24 public libraries and 11 museums; and 10 community action agencies.

	Current fiscal year 2010 appropriations	Final fiscal year 2011 funding level	Impact
Funding Allocation for Iowa (all SCSEP grantees)	\$10.5 million	\$5.6 million	— \$4.9 million
Number of Participants in Paid Community Service Employment in Iowa	1,520 persons	880 persons	— 640 persons
Number of SCSEP Hours Serving Iowa Communities	944,700 hours	507,700 hours	— 437,000 hours
Value of SCSEP Hours Serving Iowa Communities @\$16.77/hour (www.independentsector.org/volunteer__time)	\$15.8 million	\$8.5 million	— \$7.3 million

The U.S. Department of Labor awards SCSEP funding for Iowa to the AARP Foundation, Experience Works, Senior Service America, Inc., and the Iowa Dept. on Aging. Local agencies in Iowa that operate SCSEP are Community Action Agency of Siouxland, Generations Area Agency on Aging, Hawkeye Area Community Action Program, and West Central Community Action.

Impact on Alabama: A loss of \$6.4 million in SCSEP funding and \$10 million in services.

During fiscal year 2010, more than 600 local government and nonprofit programs hosted at least one SCSEP participant, including:

- Nearly 300 local government agencies and programs, including 35 libraries and 31 senior centers, and
- More than 220 nonprofit organizations, including the American Red Cross, Boys and Girls Clubs, and Chambers of Commerce.

Starting July 1, 2011, the fiscal year 2011 cut in SCSEP funding will mean over 800 fewer job opportunities and 568,000 fewer community service hours to Alabama

agencies (valued at least \$10 million, according to tables provided by the Independent Sector).

	Current fiscal year 2010 appropriations	Final fiscal year 2011 funding level	Impact
Funding Allocation for Alabama (all SCSEP grantees)	\$14.5 million	\$8.1 million	– \$6.4 million
Number of Participants in Paid Community Service Employment in Alabama	2,090 persons	1,280 persons	– 810 persons
Number of SCSEP Hours Serving Alabama Communities	1,302,000 hrs.	734,000 hrs.	– 568,000 hrs.
Value of SCSEP Hours Serving Iowa Communities @\$17.70/hour (www.independentsector.org/volunteer_time)	\$23 million	\$13 million	– \$10 million

The U.S. Department of Labor provides SCSEP funding to the Alabama Department of Senior Services, Easter Seals, and Senior Service America, Inc.

The following local government agencies in Alabama receive SCSEP funding: Alabama-Tombigbee Regional Commission, East Alabama Regional Planning and Development Commission, Jefferson County Commission, Middle Alabama Area Agency on Aging, North-central Alabama Regional Council of Governments, Northwest Alabama Council of Local Governments, South Central Alabama Development Commission, Southeast Alabama Regional Planning and Development Commission, Top of Alabama Regional Council of Governments, and West Alabama Regional Commission.

Summary

We recognize that these are challenging times for the Subcommittee and difficult funding decisions must be made. A partial restoration of SCSEP funding to \$600 million will ensure that an additional 24,000 of the hardest to reemploy, low income older workers will be able to provide an additional 7 million hours in service to communities across the Nation, with a return on investment double the appropriations provided to SCSEP. Thank you for considering this funding request.

About Senior Service America, Inc.

Senior Service America, Inc. (SSAI) has been awarded a national SCSEP grant from DOL since 1968, including competitive grants in 2003 and 2006. As the third largest national grantee, SSAI operates SCSEP exclusively through subgrants to 81 local organizations that serve 430 counties in 16 States. Its diverse network of subgrantees includes 25 area agencies on aging, 11 community action agencies, 10 regional councils of government, 13 workforce development agencies, eight faith-based organizations, two community colleges, and one local United Way.

For more information, please visit www.seniorserviceamerica.org or contact Tony Sarmiento, Executive Director, at 301-578-8469, tsarmiento@ssa-i.org,

PREPARED STATEMENT OF THE SICKLE CELL DISEASE ASSOCIATION OF AMERICA

Mr. Chairman and distinguished Members of the Subcommittee, my name is Sonja L. Banks. I was recently elected President and Chief Operating Officer of the Sickle Cell Disease Association of America, Inc (SCDAA). Since 1971, SCDAA has served as the Nation's only volunteer organization working full time on a national level to resolve issues surrounding sickle cell disease. We have grown to approximately 55 community-based member organizations focused on serving the needs of individuals with Sickle Cell Disease or Sickle Cell Trait, their families, and over 300 communities nationwide and in Canada.

On behalf of the organization, I am honored to submit this testimony to your Subcommittee as a public witness in conjunction with your consideration of fiscal year 2012 Appropriations legislation.

SCDAA respectfully urges the Subcommittee to support President Obama's continuation of funding for the Sickle Cell Anemia Demonstration Program, and the Registry and Surveillance System for Hemoglobinopathy and Hemoglobinopathy Program Initiative. We also urge the Subcommittee to restore funding to the Sickle Cell Disease and Newborn Screening Program, a crucial program to fulfilling Secretary Kathleen Sebelius' charge to the Department of Health and Human Services (HHS) to make SCD a priority area of focus.

SCD is an inherited blood disorder that is a major problem in the United States. An estimated 72,000 Americans live with the disease. More than 2.5 million Americans have the Sickle Cell Trait (SCT), including 1 in 12 African Americans. The average life span of an adult with SCD is only 45 years.

Common complications include early childhood death from infection, stroke in young children and adults, infection of the lungs similar to pneumonia, pulmonary hypertension, chronic damage to organs such as the kidney resulting in chronic kidney failure, and frequent severe painful episodes. These unpredictable, intermittent, devastating pain events can begin as early as six months of age and can span a lifetime, impacting school and work attendance.

As the Nation addresses issues associated with healthcare reform, a real and rare opportunity exists to support, a population in dire need of treatment and care through innovative research and improved care.

First, we respectfully request that the Subcommittee provide \$4,740,000 for the Sickle Cell Anemia Demonstration Program and Data Coordination Center. In fiscal year 2011, the Program received an appropriation of \$4,750,000, and for fiscal year 2012 the President's budget recommends \$4,740,000. Funding this national program will improve the lives of SCD patients through disease management programs to help them live longer, healthier lives while supporting research toward a comprehensive cure and providing community education about this disease and its treatment options.

Second, we respectfully request that the Subcommittee include \$20,165,000 for the Public Health Approach to Blood Disorders Program. The President's fiscal year 2012 budget request consolidates existing budget sub-lines into one line called "Public Health Approach to Blood Disorders." As part of this coordinated effort, a Hemoglobinopathy Data Center will operate surveillance and registry program entitled RuSH (Registry and Surveillance System for Hemoglobinopathies) in seven States for 2 years.

The RuSH health data systems will provide researchers, policy makers, and the public with imperative information about SCD and SCD-related diseases that is currently unavailable. The lack of this type of data system for Sickle-Cell-related diseases limits the research and treatment communities' ability to fully understand the impact of the disease and to develop healthcare planning at the local, State, and national levels. Additionally, funding also will support a multi-agency collaboration to form an HHS Hemoglobinopathy Program Initiative to offer more effective care and lower societal and medical costs for individuals affected by blood disorders such as SCD.

Finally, we respectfully request that the Subcommittee restore \$3,774,000 for the Sickle Cell Disease and Newborn Screening Program (SCD-NBS). Unfortunately, the President has proposed to eliminate this program in fiscal year 2012. On the other hand, Secretary Sebelius has launched an SCD initiative aimed at increasing access to and improving care. We believe that continuing the SCD-NBS program is critical to the initiative's goal, and invaluable to families and individuals suffering from this debilitating disease.

The SCD-NBS Program provides a continuity of medical services, education and counseling from birth to adulthood for persons afflicted with Sickle Cell Disease and Sickle Cell Trait. Since 2002, the project has supported a National Coordinating and Evaluation Center and 17 community-based demonstration sites across the country. Because of changes in the eligibility requirements for demonstration sites due next month, we also ask that report language be included in the fiscal year 2012 Subcommittee bill to direct the Program's funding to community-based or faith-based organizations involved with Sickle Cell Disease.

Thank you for considering these requests. We look forward to working with the Senate Appropriations Subcommittee on Labor, Health, and Education to fund these three critical programs that will help African Americans and other historically underserved children and families with Sickle Cell Disease live longer and healthier lives.

PREPARED STATEMENT OF THE SOCIETY FOR MATERNAL-FETAL MEDICINE

Mr. Chairman and Members of the Committee: The Society for Maternal-Fetal Medicine is pleased to have the opportunity to submit testimony on behalf of the fiscal year 2012 budget for the Eunice Kennedy Shriver National Institute of Child Health and Human Development (NICHD). We urge the Committee, as you move forward with your deliberations on the fiscal year 2012 budget for the National Institutes of Health (NIH), to keep in mind the enormous lost opportunities that the NIH, and in particular the NICHD, will experience if the level of funding is not sustained.

Established in 1977, the Society for Maternal-Fetal Medicine (SMFM) is dedicated to improving maternal and child outcomes; and raising the standards of prevention, diagnosis, and treatment of maternal and fetal disease.

Maternal-fetal medicine specialists, also known as MFM specialists, perinatologists, and high-risk pregnancy physicians, are highly trained obstetrician/gynecologists with advanced expertise in obstetric, medical, and surgical complications of pregnancy and their effects on the mother and fetus.

The most common medical illnesses managed by MFM's include hypertension, diabetes, seizure disorders, autoimmune diseases, and blood clotting disorders. We also provide care for women who are at increased risk for preterm birth, including multiple gestations, women with cervical insufficiency who may require a surgery to prevent preterm birth, and women with placental problems such as bleeding from premature separation. In addition, MFM specialists are often responsible for the management of preterm labor, premature rupture of membranes, and other complications during labor that have the potential to impact newborn and long-term infant outcomes.

The special problems faced by these mothers may lead to death, short-term or in some cases life-long problems for their babies. For example:

—*Pre-term birth (birth before the fetus is at 37 weeks' gestation).*—Over half a million children are born preterm each year. Preterm infants are at high risk for a variety of disorders, including mental retardation, cerebral palsy, and vision impairment. These infants are also at risk for long-term health issues, including cardiovascular disease (heart attack, stroke, and high blood pressure) and diabetes. The annual cost to society (medical, educational, and lost productivity) of preterm birth is at least \$26 billion (in 2005 dollars).

—*Hypertension.*—High blood pressure during pregnancy endangers the health of both the mother and the baby and is increasingly common as women delay pregnancy until they are older, and as they are more frequently overweight. Chronic hypertension complicating pregnancy is associated with a risk of fetal growth restriction and a risk of preterm birth. Hypertension in pregnancy is also the second leading cause of maternal death in the United States.

—*Diabetes.*—The hormonal changes of pregnancy often bring about a diabetic state (gestational diabetes) in predisposed women or can seriously worsen pre-existing diabetes. Whether diabetes mellitus existed before conception or gestational diabetes develops during pregnancy, maternal glucose intolerance can have significant medical consequences. Poorly controlled diabetes is associated with miscarriage, congenital malformations, abnormal fetal growth, stillbirth, obstructed labor, increased cesarean delivery, and neonatal complications.

NICHD's commitment to basic, clinical and translational research has led to new ways to treat and improve the health of pregnant women and infants. One of the most successful approaches for testing research questions is the NICHD Maternal-Fetal Medicine Units (MFMU) Network which allows researchers from across the country to coordinate clinical studies to improve maternal, fetal and neonatal health. The studies to date have not only identified new therapies and evaluated technologies used in maternal fetal medicine, but also have helped to abolish practices that are not useful.

—Researchers supported through the MFMU were responsible for the groundbreaking finding related to preterm birth and progesterone. Following a series of studies in the 1970s and 1980s, a national clinical trial showed that progesterone treatment resulted in a substantial reduction in the rate of preterm delivery among women who had a previous preterm birth, reduced the risk of newborn complications, and was effective in both African American and Non-African American women. This preventive therapy has been translated into practice. The drug was widely available through compounding pharmacies at a cost of \$15–\$30 per injection or \$300 for a 20 week treatment course. However, in February 2011 the FDA granted KV Pharmaceutical orphan status for its drug named Makena, a manufactured version of the identical compound drug. After which, KV Pharmaceutical increased the price of the drug to \$1,500 per injection, and later reduced it to \$690 per injection. (SMFM is actively engaged in efforts to ensure that this medication is accessible and affordable to every pregnant woman who is at risk for recurrent preterm birth.)

—Until recently, there was no evidence to show whether treating the mild form of gestational diabetes benefited or posed risks for mothers and infants. A recent Network study found women who were treated for mild gestational diabetes were half as likely to have an unusually large baby, and their babies were half as likely to experience shoulder dystocia, an emergency condition in which the baby's shoulder becomes lodged inside the mother's body during birth. Treated women in the study also had fewer caesarean deliveries. In addition, they had fewer problems with hypertension and preeclampsia, a life-threatening complication of pregnancy that can lead to maternal seizures and death. Research supported by the MFMU provided the first conclusive evidence that

treating pregnant women who have even the mildest form of gestational diabetes can reduce the risk of common birth complications among infants, as well as blood pressure disorders among mothers. These findings will change clinical practice.

- Recent research conducted by the network found that antenatal magnesium sulfate, when administered to women at risk of delivering preterm, reduces the risk of cerebral palsy in surviving preterm infants by 45 percent. This finding has been translated into clinical practice.

Cerebral palsy refers to a group of neurological disorders affecting control of movement and posture and which limit activity. The brain may be injured or develop abnormally during pregnancy, birth or in early childhood. The causes of cerebral palsy are not well understood. Both economically and emotionally, the burden of cerebral palsy is enormous. The Centers for Disease Control and Prevention (CDC) estimates the lifetime costs including direct medical, direct non-medical, and indirect for all people born with cerebral palsy in 2000 to be \$11.5 billion (in 2003 dollars).

Research that disproves a current therapy or treatment can also provide valuable guidance to clinicians and their patients.

- Translational research in the 1990s found that the use of corticosteroids in pregnancies at risk of preterm birth improved the outcomes for infants born preterm, reducing rates of breathing problems, bleeding into the brain, and problems with the intestines. However, NICHD sponsored research that evaluated the use of repeated doses of corticosteroids found that repeated doses resulted in smaller birth weights and head circumstances. Researchers also found a concerning increase in cerebral palsy in children who were exposed to four or more courses of corticosteroids. This study, along with an NIH Consensus Development Conference to pull together all available data, stopped the routine use of repeated courses of antenatal corticosteroids.

NICHD is at the forefront of several novel and important research areas, but there are still many areas about maternal health, pregnancy, fetal well-being, labor and delivery and the developing child that are not close to being understood. The challenges of the NICHD to investigate these problems remain. For example:

- Preterm Birth and Stillbirth.*—Preterm birth and stillbirth represent two of the most important complications of pregnancy. Prevention of preterm birth and stillbirth depends on identifying women at risk and understanding the mechanisms of disease. It is imperative that NICHD take advantage of high throughput technologies to understand the causes of preterm birth and stillbirth and support genomics, proteomics, and metabolomics studies focusing on prediction and prevention of preterm birth and stillbirth, as well as the use of existing biobanks. The promise of these new technologies is that a better understanding of the biologic processes involved in pregnancy and pregnancy complications will lead to improved prediction, prevention, and treatment strategies that will improve maternal and infant health.
- Severe, Early Adverse Pregnancy Outcomes.*—Women with severe, early adverse pregnancy outcome, such as multiple losses, demises, and severe preeclampsia, are at increased risk for long-term chronic health problems, including hypertension, stroke, diabetes, and obesity. Studies have shown that women who have had preeclampsia are more likely to develop chronic hypertension, to die from cardiovascular disease and to require cardiac surgery later in life. In addition, approximately 50 percent of women with gestational diabetes will develop diabetes later in life. Studies to identify women at risk for long term morbidity, and to develop strategies to prevent long term adverse outcomes in these women are urgently needed.
- Maternal Fetal Medicine Units Network.*—Vigorous support of the MFMU Network is needed so that therapies and preventive strategies that have significant impact on the health of mothers and their babies will not be delayed. Until new options are created for identifying those at risk and developing cause specific interventions, preterm birth will remain one of the most pressing problems in obstetrics.

SMFM applauds NICHD efforts to move forward with the development of a scientific vision process for the Institute that will set an ambitious agenda and inspire the Institute, the research community, and its many partners to achieve critical scientific goals and meet pressing public health needs.

Mr. Chairman, we understand the budgetary constraints that are facing the Congress, but as providers of care for women with high-risk pregnancies we have seen emerging technologies that have provided greater opportunity to evaluate and treat the complicated problems involving the mother and fetus. Without a sustained investment in the critical medical research being conducted by the National Institutes

of Health, and the National Institute of Child Health and Human Development in particular, the health of pregnant women and their babies will be at risk and NICHD's mission of promoting healthy development throughout the lifespan will be hindered.

Recommendation

The Society for Maternal-Fetal Medicine joins with the Ad Hoc Group for Medical Research in urging the Committee to provide an appropriation of \$35 billion in fiscal year 2012 for the National Institutes of Health.

The Society joins with the Friends of the National Institute of Child Health and Human Development in support of a fiscal year 2012 budget of \$1.352 billion for the National Institute of Child Health and Human Development.

Thank you for the opportunity to submit our concerns to the Committee.

PREPARED STATEMENT OF THE SOCIETY FOR NEUROSCIENCE

Introduction

Mr. Chairman and Members of the Subcommittee, my name is Susan Amara, Ph.D. I am the Thomas Detre Professor of Neuroscience and Chair of the Department of Neurobiology as well as Co-Director of the Center for Neuroscience at the University of Pittsburgh and President of the Society for Neuroscience. My major research efforts have been focused on the structure, physiology, and pharmacology of a group of proteins in the brain that are the primary targets for addictive drugs including cocaine and amphetamines, for the class of therapeutic antidepressants, known as reuptake inhibitors, and for methylphenidate, which is used to treat attention deficit hyperactivity disorders.

On behalf of the more than 41,000 members of the Society for Neuroscience (SfN) and myself, I would like to thank you for your past support of neuroscience research at the National Institutes of Health (NIH). Over the past century, researchers have made tremendous progress in understanding cell biology, physiology, and chemistry of the brain. Research funded by NIH has made it possible to make advances in brain development, imaging, genomics, circuit function, computational neuroscience, neural engineering and many other disciplines. In this testimony, I will highlight how these advances have benefited taxpayers and why we should continue to strengthen this investment, even as the Nation makes difficult budget choices.

Fiscal Year 2012 Budget Request

The Society respectfully requests that Congress provide a fiscal year 2012 appropriation in the amount of \$35 billion for NIH. This level of funding will enable the field to serve the long-term needs of the Nation by continuing to improve health for the benefit of the American people and the world, advance science, and promote America's near-term and long-range economic strength. This level will build on the research activities supported under prior year appropriations, enabling neuroscience-related NIH institutions to aggressively fund strategic plans that will significantly advance the understanding of the brain and the nervous system. In so doing, these investments will contribute to economic growth in hundreds of communities nationwide, as more than 83 percent of NIH funding is distributed to more than 3,000 institutions in communities in every State. Moreover, it will help preserve and expand America's role as leader in biomedical research, which fosters a wide range of private enterprises in the pharmaceutical, biotechnology, medical device, hospitality industries as well as many others.

SfN hopes that such an appropriation will be the first step on the path to providing a consistent and reliable long-term investment in the NIH and in particular the field neuroscience. This will ensure that there is not a dramatic drop in research activity or a loss of jobs, and serve as an inducement to keeping our young researchers in the training pipeline.

What is the Society for Neuroscience

SfN is a nonprofit membership organization of basic scientists and physicians who study the brain and nervous system. The SfN mission is to:

- Advance the understanding of the brain and the nervous system by bringing together scientists of diverse backgrounds, by facilitating the integration of research directed at all levels of biological organization, and by encouraging translational research and the application of new scientific knowledge to develop improved disease treatments and cures.
- Provide professional development activities, information and educational resources for neuroscientists at all stages of their careers, including undergradu-

- ates, graduates, and postdoctoral fellows, and increase participation of scientists from a diversity of cultural and ethnic backgrounds.
- Promote public information and general education about the nature of scientific discovery and the results and implications of the latest neuroscience research. Support active and continuing discussions on ethical issues relating to the conduct and outcomes of neuroscience research.
- Inform legislators and other policymakers about new scientific knowledge and recent developments in neuroscience research and their implications for public policy, societal benefit, and continued scientific progress.

What is Neuroscience?

Neuroscience is the study of the nervous system. It advances the understanding of human function on every level: movement, thought, emotion, behavior, and much more. Neuroscientists use tools ranging from computers to special dyes to examine molecules, nerve cells, networks, brain system, and behavior. From these studies, they learn how the nervous system develops and functions normally and what goes wrong in neurological and psychiatric disorders.

Neuroscience is now a unified field that integrates biology, chemistry, and physics with studies of structure, physiology, and behavior, including human emotional and cognitive functions. Neuroscience research includes genes and other molecules that are the basis for the nervous system, individual neurons, and ensembles of neurons that make up systems and behavior. Through their research, neuroscientists work to demonstrate normal functions of the brain and determine how the nervous system develops, matures, and maintains itself through life. They seek to prevent or cure many devastating neurological and psychiatric disorders.

As the committee works to set funding levels for critical research initiatives for fiscal year 2012 and beyond we need to do more than establish a budget that is “workable” in the context of the current fiscal situation. We ask you to help establish a national commitment to advance the understanding of the brain and the nervous system—an effort that has the potential to transform the lives of thousands of people living with brain-based diseases and disorders. Help us to fulfill our commitment to overcoming the most difficult obstacles impeding progress, and to identifying critical new directions in basic neuroscience.

Brain Research and Discoveries

The power of basic science unlocks the mysteries of the human body by exploring the structure and function of molecules, genes, cells, systems, and complex behaviors. Every day, neuroscientists are advancing scientific knowledge and medical innovation by expanding our knowledge of the basic makeup of the human brain. In doing so, researchers exploit these findings and identify new applications that foster scientific discovery which can lead to new and ground-breaking medical treatments. Basic research funded by the National Institutes of Health continues to be essential to ensuring discoveries that will inspire scientific pursuit and medical progress for future generations. The funds provided in the past have helped neuroscientists make tremendous strides in diagnosing and treating neurological and psychiatric disorders. Due to federally funded research, scientists and healthcare providers now have a much better understanding of how the brain functions.

As we look ahead to the long-term trajectory for NIH funding, steady, sustainable growth is essential to maintaining a continuous research pipeline that spans from basic science to clinical outcomes. Without a long-term sustainable plan for investing in research, dramatic swings in the funding cycle have a stifling, often irreversible impact on progress, shutting down laboratories, driving away talented young investigators and disillusioning students who have just discovered a passion for biomedical research. As support declines, gaps emerge between levels of funding and the need for scientific advance. There are two kinds of gap—the ones you see and the ones you don’t. In times of limited resources, it is easier to deal strategically with the gaps you know. For example, with an aging population it makes sense to maintain support for research on Alzheimer’s and other chronic neurodegenerative diseases. But it’s the gaps we are unaware of that I also worry about. We know from past experience that it is not always clear where the next critical breakthrough or innovative approach will come from—progress in science depends on imaginative curiosity-driven research that makes leaps in ways no one could have anticipated. Where would neuroscience and cell biology be without a rainbow of fluorescent proteins from jellyfish, which are now illuminating neurological diseases and disorders? Where would cutting edge work in systems neuroscience be today without research on channel rhodopsins from algae, which now hold promise for novel, noninvasive treatments for brain disorders? When resources are limited, balancing support for high-risk high-payoff ideas with disease-driven translational research presents a

huge challenge—it is easy to see why the latter is important, yet ultimately both kinds of research have the potential to contribute to the development of life-changing therapies and cures for different diseases. More than ever is it important to support and fund research at many levels from the most basic to translational. The following are just two of the many basic research success stories in neuroscience research emerging now thanks to strong historic investment in NIH and other research agencies:

Nicotine Addiction

Although tobacco has been used legally for hundreds of years, nicotine addiction takes effect through pathways similar to those involving cocaine and heroin. During addiction, drugs activate brain areas that are typically involved in the motivation for other pleasurable rewards such as eating or drinking. These addictions leave the body with a strong chemical dependence that is very hard to get over. In fact, almost 80 percent of smokers who try to quit fail within their first year. The lack of a reliable cessation technique has profound consequences. Tobacco-related illnesses kill as many as 440,000 Americans every year, and thus the human and economic costs of nicotine addiction are staggering. One out of every five U.S. deaths is related to smoking.

Past Federal funding has enabled scientists to understand the mechanisms of nicotine addiction, enabling them develop successful treatments for smoking cessation. The discoveries that lead to these findings started back in the 1970's, when scientists identified the substance in the brain that nicotine acted on to transmit its pleasurable effects. They found that nicotine was hijacking a receptor, a protein used by the brain to transmit information. This receptor, called the nicotinic acetylcholine receptor, regulates the release of another key transmitter, dopamine, which in turn acts within reward circuits of the brain to mediate both the positive sensations and eventual addiction triggered by nicotine consumption. This knowledge has been the basis for the development of several therapeutic strategies for smoking cessation: nicotine replacement, drugs that target nicotine receptors, as well as drugs that prevent the reuptake of dopamine have all been shown to increase the long-term odds of quitting by several fold.

More recently, using mice genetically modified to have their nicotinic acetylcholine receptors contain one specific type of subunit, scientists determined that some kinds of receptor subunits are more sensitive to nicotine than others, and because each subunit is generated from its own gene, this discovery indicated that genetics can influence how vulnerable a person is to nicotine addiction. Further research to spot genetic risk factors and to generate genetically tailored treatment options is ongoing. Other studies are also testing whether a vaccine that blocks nicotine's effects can help discourage the habit. Since people who are able to quit smoking immediately lower their risk for certain cancers, heart disease and stroke, reliable and successful treatments are clearly needed. Today's continued research funding can make it possible for these emerging therapies to ultimately help people overcome the challenges of nicotine addiction.

Brain-machine interface

The brain is in constant communication with the body in order to perform every minute motion from scratching an itch to walking. Paralysis occurs when the link between the brain and a part of the body is severed, and eliminates the control of movement and the perception of feeling in that area. Almost 2 percent of the U.S. population is affected by some sort of paralysis resulting from stroke, spinal cord or brain injury as well as many other causes. Previous research has focused on understanding the mechanisms by which the brain controls a movement. Research during which scientists were able to record the electrical communication of almost 50 nerve cells at once showed that multiple brain cells work together to direct complex behaviors. However, in order to use this information to restore motor function, scientists needed a way to translate the signals that neurons give into a language that an artificial device could understand and convert to movement.

Basic science research in mice led to the discovery that thinking of a motion activated nerve cells in the same way that actually making the movement would. Further studies showed that a monkey could learn to control the activity of a neuron, indicating that people could learn to control brain signals necessary for the operation of robotic devices. Thanks to these successes, brain-controlled prosthetics are being tested for human use. Surgical implants in the brain can guide a machine to perform various motor tasks such as picking up a glass of water. These advances, while small, are a huge improvement for people suffering from paralysis. Scientists hope to eventually broaden the abilities of such devices to include thought-controlled speech and more. Further research is also needed to develop non-invasive interfaces

for human-machine communication, which would reduce the risk of infection and tissue damage. Understanding how neurons control movement has had and will continue to have profound implications for victims of paralysis.

A common theme of both these examples of basic research success stories is that they required the efforts of basic science researchers discovering new knowledge, of physician scientists capable adapting those discoveries into better treatments for their patients and of companies willing to build on all of this knowledge to develop new medications and devices.

The future of American science

Finally, as the subcommittee considers this year's funding levels and in future years, I hope that the members will consider that significant advancements in the biomedical sciences often come from younger investigators who bring new insights and approaches to bear on old or intractable problems. Without sustained investment, I fear that flat or falling funding will begin to take a toll on the imagination, energy and resilience of younger investigators and I wonder about the impact of these events on the next generation. America's scientific enterprise—and its global leadership—has been built over generations, but without sustained investment, we could lose that leadership quickly, and it will be difficult to rebuild. When we undermine a research enterprise—whether a single lab or a national infrastructure built through decades of Federal funding—it is a loss to us all and difficult to recover. In the United States—traditionally a pacesetter for strong investment—threatened cuts in science funding jeopardize a global training system that fosters and encourages scientific creativity, flexibility, and enterprise. As a young girl interested in science, I was inspired by the idea that the United States was a place where anyone with imagination, drive, and a passion for research could come, learn, and potentially do something great. Without funding, that culture of entrepreneurship and curiosity—driven research could be hindered for decades.

Conclusion

We live at a time of extraordinary opportunity in neuroscience. When I read an exciting research article, I get a sense of awe and pride at the extraordinary progress in our field. A myriad of questions once impossible to consider are now within reach as a consequence of new technologies, an ever-expanding knowledge base, and a willingness to embrace many disciplines.

As a result of NIH investments, the field of neuroscience research holds great potential for making great progress to understand basic biological principles and for addressing the numerous neurological and psychiatric illnesses that strike more than 100 million Americans annually. And we have entered an era in which knowledge of nerve cell function has brought us to the threshold of a more profound understanding of behavior and of the mysteries of the human mind. However, continued progress can only be accomplished by a consistent and reliable funding source.

An NIH appropriation of \$35 billion for fiscal year 2012 and sustained reliable growth is required to take the research to the next level in order to improve the health of Americans and to maintain American leadership in science worldwide. As a field we look forward to realizing that goal. Thank you for this opportunity to testify.

PREPARED STATEMENT OF THE SOCIETY FOR WOMEN'S HEALTH RESEARCH

The Society for Women's health Research (SWHR) and the Women's Health Research Coalition (WHRC), is pleased to have the opportunity to submit the following testimony in support of ongoing Federal funding for biomedical research—specifically sex differences and total women's health research—within the Department of Health and Human Services (HHS) at the National Institutes of Health (NIH), Centers for Disease Control and Prevention (CDC), and the Agency for Healthcare and Research Quality (AHRQ).

SWHR and WHRC believe that sustained funding for biomedical and women's health research programs conducted and supported across the Federal agencies is absolutely essential if the United States is going to meet the health needs of women and men. A well-designed and appropriately funded Federal research agenda does more than avoid dangerous and expensive "trial and error" medicine for patients—it advances the Nation's research capability, continues growth in a sector with proven return on investment, and takes a proactive approach to maintaining America's position as world-wide leader in medical research, education, and development.

SWHR and WHRC believe that sustained funding for biomedical and women's health research programs conducted and supported across the Federal agencies is

absolutely essential if the United States is to meet the health needs of women, and men, and advance the nation's research capability.

As President Obama stated in his State of the Union Address, investment in biomedical research "will strengthen our security, protect our planet, and create countless new jobs for our people". Proper investment in health research will save valuable dollars that are currently wasted on inappropriate treatments and procedures. Further, SWHR and WHRC want targeted research into sex differences that will help in determining targeted treatments that will help women and men to receive quality appropriate care.

National Institutes of Health

Past Congressional investment for the NIH positioned the United States as the world's leader in biomedical research and has provided a direct and significant impact on women's health research and the careers of women scientists over the last decade. In recent years, that investment has declined along with America's place as the Number 1 in biomedical research. These two facts are interrelated. Cutting NIH funding threatens scientific advancement, substantially delays cures becoming available in the United States, and puts the innovative research practices and reputation that America is known for in jeopardy.

When faced with budget cuts, NIH is left with no other option but to reduce the number of grants it is able to fund. The number of new grants funded by NIH had dropped steadily with declining budgets, growing at a percent less than that of inflation since fiscal year 2003. Cuts to investments in biomedical research also negatively impact the economy. A shrinking pool of available grants has a significant impact on scientists who depend upon NIH support to cover both salaries and laboratory expenses to conduct high quality biomedical research, putting both medical advancement and job creation at risk. More than 83 percent of NIH funding is spent in communities across the Nation, creating jobs at more than 3,000 universities, medical schools, teaching hospitals, and other research institutions in every State.

Reducing the number of grants available to researchers further decreases publishing of new findings and decreases the number of scientists gaining experience in research, both reducing a scientist's likelihood of achieving tenure in a university setting. New and less established researchers are forced to consider other careers, or take positions outside the United States, and results in the loss of the skilled bench scientists and researchers so desperately needed to sustain America's cutting edge in biomedical research.

While the U.S. deficit requires careful consideration of all funding and investments, cutting relatively small discretionary funding within the NIH budget will not make a substantial impact on the deficit, but will drastically hamper the ability of the United States to remain the global leader in biomedical research. SWHR and WHRC recommend that Congress set, at a minimum, a budget that matches the administration's request for a \$1 billion increase for NIH for fiscal year 2012.

Study of Sex Differences

It has only been within the past decade that scientists have begun to uncover the significant biological and physiological differences between women and men and its impact health and medicine. Sex-based biology, the study of biological and physiological differences between women and men, has revolutionized the way that the scientific community views the sexes. Sex differences play an important role in disease susceptibility, prevalence, time of onset and severity and are evident in cancer, obesity, heart disease, immune dysfunction, mental health disorders, and many other illnesses. Medications can have different effects in woman and men, based on sex specific differences in absorption, distribution, metabolism and elimination. It is imperative that research addressing these important differences be supported and encouraged.

SWHR recommends that NIH, with the funds provided, report sex/gender differences in all research findings. Further, NIH should seek to expand its inclusion of women in basic, clinical and medical research to Phase I, II, and III studies. By currently only mandating sufficient female subjects in Phase III, researchers often miss out on the chance to look for variability by sex in the early phases of research, where scientists look at treatment safety and determine safe and effective dose levels for new medications. By mandating that sex differences research occur in earlier phases of clinical research studies, the NIH can continue to serve as a role model for industry research, as well as other nations. Only by gaining more information on how therapies work in women will medicine be able to advance toward more targeted and effective treatments for all patients, women and men alike.

Office of Research on Women's Health

The NIH's Office of Research on Women's Health (ORWH) serves as the focal point for coordinating women's health and sex differences research at NIH, advising the NIH Director on matters relating to research on women's health and sex differences research, strengthening and enhancing research related to diseases, disorders, and conditions that affect women; working to ensure that women are appropriately represented in research studies supported by NIH; and developing opportunities for and support of recruitment, retention, re-entry and advancement of women in biomedical careers. In September 2010, ORWH celebrated its 20th anniversary and unveiled a new strategic plan for women's health and sex difference research, *Moving Into The Future With Dimensions and Strategies: A Vision For 2020 For Women's Health Research*.

BIRCWH and SCOR

The Building Interdisciplinary Research Careers in Women's Health (BIRCWH) and Specialized Centers of Research on Sex and Gender Factors Affecting Women's Health (SCOR) are two ORWH programs that benefit the health of both women and men through sex and gender research, interdisciplinary scientific collaboration, and provide tremendously important support for young investigators in a mentored environment.

The BIRCWH program, created in 2000, is an innovative, trans-NIH career development program that provides protected research time for junior faculty by pairing them with senior investigators in an interdisciplinary mentored environment. Each BIRCWH receives approximately \$500,000 a year, most from the ORWH budget. To date, 407 scholars have been trained in 41 centers, and 80 percent of those scholars are female. The BIRCWH centers have produced over 1,300 publications, 750 abstracts, 200 NIH grants and 85 awards from industry and institutional sources.

SCORs, established in 2003, are designed to increase innovative, interdisciplinary research focusing on sex differences and major medical problems that affect women through centers that facilitate basic, clinical, and translational research. Each SCOR program results in unique research and in 2010, resulted in over 150 published journal articles, 214 abstracts and presentations and 44 other publications.

Additionally, ORWH has created several additional programs to advance the science of sex differences research and research into women's health. The Advancing Novel Science in Women's Health Research (ANSWHR) program, created in 2007, promotes innovative new concepts and interdisciplinary research in women's health research and sex/gender differences. The Research Enhancement Awards Program (REAP) supports meritorious research on women's health that otherwise would have missed the IC pay line.

In addition to its funding of research on women's health and sex differences research, ORWH has established several methods for dissemination information about women's health and sex differences research. ORWH created the Women's Health Resources web portal in collaboration (<http://www.womenshealthresources.nlm.nih.gov>) with that National Library of Medicine, to serve as a resource for researchers and consumers on the latest topics in women's health and uses social media to connect the public to health awareness campaigns.

To allow ORWH's programs and research grants to continue make their impact on research and the public, Congress must direct that NIH continue its support of ORWH and provide it with \$1 million budget increase, bringing its fiscal year 2012 total to \$43.9 million.

Health and Human Services' Office of Women's Health

The HHS Office of Women's Health (OWH) is the Government's champion and focal point for women's health issues. It works to redress inequities in research, healthcare services, and education that have historically placed the health of women at risk. Without OWH's actions, the task of translating research into practice would be only more difficult and delayed.

Under HHS, the agencies currently with offices, advisors or coordinators for women's health or women's health research include the Food and Drug Administration, Centers for Disease Control and Prevention, Agency for Healthcare Quality and Research, Indian Health Service, Substance Abuse and Mental Health Services Administration, Health Resources and Services Administration, and Centers for Medicare and Medicaid Services. It is imperative that these offices are funded at levels which are adequate for them to perform their assigned missions, and are sustainable so as to support needed changes in the long term. We ask that the committee report reflect Congress's support for these Federal women's health offices, and recommend that they are appropriately funded on a permanent basis to ensure that these programs can continue and be strengthened in the coming fiscal year.

It is only through consistent funding that the OWH will be able to achieve its goals. The budgets for these offices have been flat-lined in recent years, which results in effectively a net decrease due to inflation. Considering the impact of women's health programs from OWH on the public, we urge Congress to provide an increase of \$1 million for the HHS OWH, a total \$34.7 million requested for fiscal year 2012.

Centers for Disease Control and Prevention

SWHR supports the national and international work of the CDC, especially the work of CDC's Office of Women's Health (OWH). While SWHR is delighted that the CDC's OWH is now codified in statute, we are concerned that proposed cuts to the CDC budget by the administration will significantly jeopardize programs that benefit women, leaving them with even fewer options for sound clinical information. Research and clinical medicine are still catching up from decades of a male-centric focus, and when diseases strike women, there remains a paucity of basic knowledge on how diseases affect female biology, a lack of drugs that have been adequately tested in women, and now even fewer options for information through the many educational outreach programs of the CDC.

The OWH within CDC is fundamental to promoting and improving the health, safety, and quality of life of women across their lifespan. The office led the CDC in the collaboration and development of text4baby, which sends free text messages on health and pregnancy issues, to pregnant women and new moms. In the year since its launch, over 135,000 subscribers have signed up for the service and millions of text messages have been sent. More than 300 outreach partners, including national, State, business, academic, nonprofit, and other groups, help to promote the service.

With its small budget, the OWH actively participated with others in CDC, HHS, and the State Department in the early development of the Global Health Initiative, and routinely collaborates with other agencies to advance the knowledge and research into women's health issues. This year, OWH worked closely with HHS OWH on the development of the Action Agenda on Women's Health: Beyond 2010 and with NIH on the development of the research conference on Advances in Uterine Leiomyoma. SWHR and WHRC recommend that Congress provide the CDC OWH with a 1.06 percent increase for fiscal year 2012, bringing their total to \$478,000.

Agency for Healthcare Research and Quality

The Agency for Healthcare Research and Quality's work serves as a catalyst for change by promoting the results of research findings and incorporating those findings into improvements in the delivery and financing of healthcare. Through AHRQ's research projects, lives have been saved. For example, it was AHRQ who first discovered that women treated in emergency rooms are less likely to receive life-saving medication for a heart attack. AHRQ funded the development of two software tools, now standard features on hospital electrocardiograph machines, which have improved diagnostic accuracy and dramatically increased the timely use of "clot-dissolving" medications in women having heart attacks. As efforts to improve the quality of care, not just the quantity of care, progress, findings such as these coming out of AHRQ reveal where relatively modest investments can offer significant improvement to women's health outcomes, as well as a better return on investment for scarce healthcare dollars.

While AHRQ has made great strides in women's health research, its budget has been dismally funded for years, though targeted funding increases in recent years for dedicated projects, including funds from the American Recovery and Reinvestment Act (ARRA), moved AHRQ in the right direction. ARRA funds more than doubled AHRQ's investment in patient-centered research relevant to women. AHRQ is now supporting studies that examining comparative effectiveness in diabetes and breast cancer prevention in women, and comprehensive care for adults with serious mental illness.

With the ARRA funds, total investment in women's health increased from \$52 million to \$109 million, however, more core and sustained funding is needed to help AHRQ continue doing the research that helps patients and doctors make better medical decisions. Lack of investment in AHRQ will hinder advancements that will improve medical decisionmaking of doctors and patients and will result in improved health outcomes. Any decreased level of funding seriously jeopardizes the research and quality improvement programs that Congress mandates from AHRQ.

SWHR and WHRC recommend Congress fund AHRQ at \$405 million for fiscal year 2012, an increase 2 percent over 2010 enacted levels. This investment ensures that adequate resources are available for high priority research, including women's healthcare, sex- and gender-based analyses, and health disparities—valuable infor-

mation that can help to better personalize treatments, lower overall medical spending, and improve outcomes for female and male patients nationwide.

In conclusion, Mr. Chairman, we thank you and this Committee for its strong record of support for medical and health services research and its commitment to the health of the Nation through its support of peer-reviewed research. We look forward to continuing to work with you to build a healthier future for all Americans.

PREPARED STATEMENT OF THE SPINA BIFIDA ASSOCIATION

Background and Overview

On behalf of the estimated 166,000 individuals and their families who are affected by all forms of Spina Bifida—the Nation’s most common, permanently disabling birth defect—Spina Bifida Association (SBA) appreciates the opportunity to submit public written testimony for the record regarding fiscal year 2012 funding for the National Spina Bifida Program and other related Spina Bifida initiatives. SBA is a national voluntary health agency, working on behalf of people with Spina Bifida and their families through education, advocacy, research and service. SBA stands ready to work with Members of Congress and other stakeholders to ensure our Nation mounts and sustains a comprehensive effort to reduce and prevent suffering from Spina Bifida.

Spina Bifida, a neural tube defect (NTD), occurs when the spinal cord fails to close properly within the first few weeks of pregnancy and most often before the mother knows that she is pregnant. Over the course of the pregnancy—as the fetus grows—the spinal cord is exposed to the amniotic fluid, which increasingly becomes toxic. It is believed that the exposure of the spinal cord to the toxic amniotic fluid erodes the spine and results in Spina Bifida. There are varying forms of Spina Bifida occurring from mild—with little or no noticeable disability—to severe—with limited movement and function. In addition, within each different form of Spina Bifida the effects can vary widely. Unfortunately, the most severe form of Spina Bifida occurs in 96 percent of children born with this birth defect.

The result of this NTD is that most people with it suffer from a host of physical, psychological, and educational challenges—including paralysis, developmental delay, numerous surgeries, and living with a shunt in their skulls, which seeks to ameliorate their condition by helping to relieve cranial pressure associated with spinal fluid that does not flow properly. As we have testified previously, the good news is that after decades of poor prognoses and short life expectancy, children with Spina Bifida are now living into adulthood and increasingly into their advanced years. These gains in longevity, principally, are due to breakthroughs in research, combined with improvements generally in healthcare and treatment. However, with this extended life expectancy, our Nation and people with Spina Bifida now face new challenges, such as transitioning from pediatric to adult healthcare providers, education, job training, independent living, healthcare for secondary conditions, and aging concerns, among others. Individuals and families affected by Spina Bifida face many challenges—physical, emotional, and financial. Fortunately, with the creation of the National Spina Bifida Program in 2003, individuals and families affected by Spina Bifida now have a national resource that provides them with the support, information, and assistance they need and deserve.

As is discussed below, the daily consumption of 400 micrograms of folic acid by women of childbearing age, prior to becoming pregnant and throughout the first trimester of pregnancy, can help reduce the incidence of Spina Bifida, by up to 70 percent. The Centers for Disease Control and Prevention (CDC) calculates that there are approximately 3,000 NTD births each year, of which an estimated 1,500 are Spina Bifida, and, as such, with the aging of the Spina Bifida population and a steady number of affected births annually, the Nation must take additional steps to ensure that all individuals living with this complex birth defect can live full, healthy, and productive lives.

Cost of Spina Bifida

It is important to note that the lifetime costs associated with a typical case of Spina Bifida—including medical care, special education, therapy services, and loss of earnings—are as much as \$1 million. The total societal cost of Spina Bifida is estimated to exceed \$750 million per year, with just the Social Security Administration payments to individuals with Spina Bifida exceeding \$82 million per year. Moreover, tens of millions of dollars are spent on medical care paid for by the Medicaid and Medicare programs. Efforts to reduce and prevent suffering from Spina Bifida will help to not only save money, but will also save—and improve—lives.

Improving Quality-of-Life through the National Spina Bifida Program

Since 2001, SBA has worked with Members of Congress and staff at the CDC to help improve our Nation's efforts to prevent Spina Bifida and diminish suffering—and enhance quality-of-life—for those currently living with this condition. With appropriate, affordable, and high-quality medical, physical, and emotional care, most people born with Spina Bifida will likely have a normal or near normal life expectancy. The CDC's National Spina Bifida Program works on two critical levels—to reduce and prevent Spina Bifida incidence and morbidity and to improve quality-of-life for those living with Spina Bifida.

The National Spina Bifida Program established the National Spina Bifida Resource Center housed at the SBA, which provides information and support to help ensure that individuals, families, and other caregivers, such as health professionals, have the most up-to-date information about effective interventions for the myriad primary and secondary conditions associated with Spina Bifida. Among many other activities, the program helps individuals with Spina Bifida and their families learn how to treat and prevent secondary health problems, such as bladder and bowel control difficulties, learning disabilities, depression, latex allergies, obesity, skin breakdown, and social and sexual issues. Children with Spina Bifida often have learning disabilities and may have difficulty with paying attention, expressing or understanding language, and grasping reading and math. All of these problems can be treated or prevented, but only if those affected by Spina Bifida—and their caregivers—are properly educated and given the skills and information they need to maintain the highest level of health and well-being possible. The National Spina Bifida Program's secondary prevention activities represent a tangible quality-of-life difference to the estimated 166,000 individuals living with all forms of Spina Bifida, with the goal being living well with Spina Bifida.

An important resource to better determine best clinical practices and the most cost effective treatments for Spina Bifida is the National Spina Bifida Registry, now in its third year. Nine sites throughout the Nation are collecting patient data, which supports the creation of quality measures and will assist in improving clinical research that will truly save lives, while also realizing a significant cost savings.

SBA understands that the Congress and the Nation face unprecedented budgetary challenges. However, the progress being made by the National Spina Bifida Program must be sustained to ensure that people with Spina Bifida—over the course of their lifespan—have the support and access to quality care they need and deserve. To that end, SBA respectfully urges the Subcommittee to Congress allocate \$6.25 million (level funding) in fiscal year 2012 to the program, so it can continue and expand its current scope of work; further develop the National Spina Bifida Patient Registry; and sustain the National Spina Bifida Resource Center. Sustaining funding for the National Spina Bifida Program will help ensure that our Nation continues to mount a comprehensive effort to prevent and reduce suffering from—and the costs of—Spina Bifida.

Preventing Spina Bifida

While the exact cause of Spina Bifida is unknown, over the last decade, medical research has confirmed a link between a woman's folate level before pregnancy and the occurrence of Spina Bifida. Sixty-five million women of child-bearing age are at-risk of having a child born with Spina Bifida. As mentioned above, the daily consumption of 400 micrograms of folic acid prior to becoming pregnant and throughout the first trimester of pregnancy can help reduce the incidence of Spina Bifida, by up to 70 percent. There are few public health challenges that our nation can tackle and conquer by nearly three-fourths in such a straightforward fashion. However, we must still be concerned with addressing the 30 percent of Spina Bifida cases that cannot be prevented by folic acid consumption, as well as ensuring that all women of childbearing age—particularly those most at-risk for a Spina Bifida pregnancy—consume adequate amounts of folic acid prior to becoming pregnant.

Since 1968, the CDC has led the Nation in monitoring birth defects and developmental disabilities, linking these health outcomes with maternal and/or environmental factors that increase risk, and identifying effective means of reducing such risks. The good news is that progress has been made in convincing women of the importance of folic acid consumption and the need to maintain a diet rich in folic acid. This public health success should be celebrated, but still too many women of childbearing age consume inadequate daily amounts of folic acid prior to becoming pregnant, and too many pregnancies are still affected by this devastating birth defect. The Nation's public education campaign around folic acid consumption must be enhanced and broadened to reach segments of the population that have yet to heed this call—such an investment will help ensure that as many cases of Spina Bifida can be prevented as possible.

The goal is to increase awareness of the benefits of folic acid, particularly for those at elevated risk of having a baby with neural tube defects (those who have Spina Bifida themselves, or those who have already conceived a baby with Spina Bifida). With continued funding in fiscal year 2012, CDC's folic acid awareness activities could be expanded to reach the broader population in need of these public health education, health promotion, and disease prevention messages. SBA advocates that Congress provide adequate funding to CDC to allow for a targeted public health education and awareness focus on at-risk populations (e.g., Hispanic-Latino communities) and health professionals who can help disseminate information about the importance of folic acid consumption among women of childbearing age.

In addition to a \$6.25 million fiscal year 2012 allocation for the National Spina Bifida Program, SBA urges the Subcommittee to provide \$5.126 million for the CDC's national folic acid education and promotion efforts to support the prevention of Spina Bifida and other NTD; \$26.342 million to strengthen the CDC's National Birth Defects Prevention Network; and \$144 million to fund the National Center on Birth Defects and Developmental Disabilities.

Improving Health Care for Individuals with Spina Bifida

As you know, Agency for Health Research and Quality's (AHRQ) mission is to improve the outcomes and quality of healthcare, reduce healthcare costs, improve patient safety, decrease medical errors, and broaden access to essential health services. AHRQ's work is vital to the evaluation of new treatments, which helps ensure that individuals living with Spina Bifida continue to receive state-of-the-art care and interventions. To that end, we request a \$405 million fiscal year 2012 allocation for AHRQ, to help improve quality of care and outcomes for people with Spina Bifida.

Sustain and Seize Spina Bifida Research Opportunities

Our Nation has benefited immensely from our past Federal investment in biomedical research at the NIH. SBA joins with other in the public health and research community in advocating that NIH receive increased funding in fiscal year 2012. This funding will support applied and basic biomedical, psychosocial, educational, and rehabilitative research to improve the understanding of the etiology, prevention, cure and treatment of Spina Bifida and its related conditions. In addition, SBA respectfully requests that the Subcommittee include the following language in the report accompanying the fiscal year 2012 L-HHS appropriations measure:

"The Committee encourages NIDDK, NICHD, and NINDS to study the causes and care of the neurogenic bladder in order to improve the quality of life of children and adults with Spina Bifida; to support research to address issues related to the treatment and management of Spina Bifida and associated secondary conditions, such as hydrocephalus; and to invest in understanding the myriad co-morbid conditions experienced by children with Spina Bifida, including those associated with both paralysis and developmental delay."

Conclusion

Please know that SBA stands ready to work with the Subcommittee and other Members of Congress to advance policies and programs that will reduce and prevent suffering from Spina Bifida. Again, we thank you for the opportunity to present our views regarding fiscal year 2012 funding for programs that will improve the quality-of-life for the estimated 166,000 Americans and their families living with all forms of Spina Bifida.

PREPARED STATEMENT OF THE AIDS INSTITUTE

The AIDS Institute, a national public policy research, advocacy, and education organization, is pleased to comment in support of critical HIV/AIDS and Hepatitis programs as part of the fiscal year 2012 Labor, Health and Human Services, Education and Related Agencies appropriation measure. We thank you for your past support of these programs and hope you will do your best to adequately fund them in the future in order to provide for and protect the public health.

HIV/AIDS

HIV/AIDS remains one of the world's worst health pandemics in history. According to the CDC, over 617,000 people have died of AIDS in the United States and there are 56,300 new infections each year. At the end of 2007, an estimated 1.1 million people in the United States were living with HIV/AIDS. Persons of minority races and ethnicities are disproportionately affected. African Americans account for

half of the cases. HIV/AIDS disproportionately affects the poor and about 70 percent of those infected rely on publicly funded healthcare.

The vast majority of the discretionary programs supporting HIV/AIDS efforts domestically are funded through your Subcommittee. The AIDS Institute, working in coalition, has developed funding requests for each of these programs. We ask that you do your best to adequately fund them at the requested level.

We are keenly aware of budget constraints and competing interests for limited dollars, but programs that prevent and treat HIV are inherently Federal, as they help protect the public health against a highly infectious virus, which if left untreated will most likely lead to death and increased infections. Federal funding is particularly critical at this time since State and local budgets are being severely cut during the economic downturn.

National HIV/AIDS Strategy

President Obama released a comprehensive National HIV/AIDS Strategy (NHAS) which seeks to reduce new HIV infections, increase access to care and improving health outcomes for people living with HIV, and reduce HIV-related health disparities. The Strategy sets ambitious goals and seeks a more coordinated national response with a focus on those communities most affected and on programs that work. In order to attain the goals, additional investment will be needed and health reform must be implemented.

The budget proposed by the President requests that up to 1 percent of HHS discretionary funds appropriated for domestic HIV/AIDS activities be provided to the Office of the Assistant Secretary for Health to foster collaborations across HHS agencies and finance high priority initiatives in support of the NHAS. Such initiatives would focus on improving linkages between prevention and care, coordinating Federal resources within targeted high-risk populations, enhancing provider capacity, and monitoring key Strategy targets. The AIDS Institute supports this provision and encourages you to include it in the fiscal year 2012 appropriation measure.

Centers for Disease Control and Prevention—HIV Prevention and Surveillance

Fiscal year 2011—\$800.4 million

Fiscal year 2012 community request—\$1,325.7 million

The United States allocates only about 4 percent of its domestic HIV/AIDS spending on prevention. Investing in prevention today will save money tomorrow. Preventing all the new 56,000 cases in just one year would translate into an astounding \$20 billion in lifetime medical costs.

The CDC is focused on carrying out several goals of the NHAS by 2015. Specifically, they are seeking to lower the annual number of new infections by 25 percent, reduce the HIV transmission rate by 30 percent, and increase from 79 to 90 the percentage of people living with HIV who know their serostatus.

While it is estimated that an increase of over \$500 million would be needed to achieve the goals of the NHAS, The AIDS Institute supports an increase of at least the \$57.2 million over fiscal year 2011 as the President has proposed, including \$30.4 million from the Prevention and Public Health Fund. We are also supportive of a transfer of \$40 million from the Chronic Disease Prevention and Public Health Promotion for HIV school health programs to achieve closer coordination of CDC's HIV prevention programs.

With this funding, the CDC would improve surveillance and use of community viral load, enhance prevention among most affected communities, integrate care and prevention, expand HIV testing and linkage to care, build capacity, develop social marketing campaigns, and improve monitoring.

Ryan White HIV/AIDS Programs

Fiscal year 2011—\$2,336.7 million

Fiscal year 2012 community request—\$2,687.0 million

The centerpiece of the Government's response to caring and treating low-income people with HIV/AIDS is the Ryan White HIV/AIDS Program, which currently serves over half a million low-income, uninsured, and underinsured people. In fiscal year 2011, almost all parts of the Program experienced funding cuts at a time of increased need and demands on the program. Consider the following:

- Caseloads are increasing. People are living longer due to lifesaving medications, there are over 56,000 new infections each year, and increased testing programs identify thousands of new people infected with HIV. With rising unemployment, people are losing their employer-sponsored health coverage.
- State and local budgets are experiencing cutbacks due to the economic downturn. A survey by the National Alliance of State and Territorial AIDS Directors

found that State funding reductions totaled more than \$170 million in 29 States during fiscal year 2009.

- States are cutting and the Federal Government is proposing massive cuts to Medicaid. As the payer of last resort cuts to entitlement programs, such as Medicaid, place further pressure on the Ryan White Program.
- There are significant numbers of people in the United States who are not receiving life-saving AIDS medications. An IOM report concluded that 233,069 people in the United States who know their HIV status do not have continuous access to Highly Active Antiretroviral Therapy.

Specifically, The AIDS Institute requests the following funding levels for each part of the Program:

Part A provides medical care and vital support services for persons living with HIV/AIDS in the metropolitan areas most affected by HIV/AIDS. We request an increase of \$74.2 million, for a total of \$752 million.

Part B base provides essential services including diagnostic, viral load testing and viral resistance monitoring, and HIV care to all 50 States, District of Columbia, Puerto Rico, and the territories. We are requesting a \$76.8 million increase, for a total of \$495 million.

The AIDS Drug Assistance Program (ADAP) provides life-saving HIV drug treatment to over 200,000 people, or about one in four HIV positive people in care in the United States. The majority of whom are people of color and very poor. ADAPs are experiencing unprecedented growth and are in crisis. Over the course of 1 year, HRSA reported an increase of over 30,000 new people to the program. Because of a lack of funding, there are currently 8,100 people in 13 States on waiting lists, thousands more have been removed from the program due to lowered eligibility requirements, and drug formularies have been reduced.

According to NASTAD's recent annual ADAP monitoring report, State funding for ADAPs increased 61 percent in fiscal year 2009 to a total of \$346 million, and drug company rebates grew 5 percent to \$522 million. The Federal share of the overall ADAP budget has decreased to less than 50 percent.

The AIDS Institute is very appreciative of the \$50 million increase to ADAP in fiscal year 2011, but it is far from what is currently required to meet the growing number of new people needing ADAP medications in the coming year. The true need is an increase of \$360 million. The AIDS Institute requests that you provide an increase that is as close as possible to that amount. We note the President has requested an increase of \$55 million, which would only provide medications to fewer than 4,800 people.

Part C provides early medical intervention and other supportive services to over 248,000 people at over 380 directly funded clinics. We are requesting a \$66.6 million increase, for a total of \$272 million.

Part D provides care to over 84,000 women, children, youth, and families living with and affected by HIV/AIDS. We are requesting a \$5.8 million increase, for a total of \$83.1 million.

Part F includes the AIDS Education and Training Centers (AETCs) program and the Dental Reimbursement program. We are requesting a \$15.4 million increase for the AETC program, for a total of \$50 million, and a \$5.5 million increase for the Dental Reimbursement program, for a total of \$19 million.

National Institutes of Health—AIDS Research

Fiscal year 2011—\$3.07 billion

Fiscal year 2012 community request—\$3.5 billion

The NIH conducts research to better understand HIV and its complicated mutations, discover new drug treatments, develop a vaccine and other prevention programs such as microbicides, and ultimately develop a cure. The critically important work performed by the NIH not only benefits those in the United States, but the entire world. This research has already helped in the development of many highly effective new drug treatments, prolonging the lives of millions of people. NIH also conducts the necessary behavioral research to learn how HIV can be prevented best in various affected communities. We ask the Committee to fund critical AIDS research at the community requested level of \$3.5 billion.

Comprehensive Sexuality Education

Since the vast majority of HIV infection occurs through sex, age appropriate education on how HIV is transmitted and HIV prevention is critical. It is for this reason, The AIDS Institute is supportive of funding the Teen Pregnancy Prevention Initiative for a total of \$135 million and we oppose funding of abstinence only education programs, which have proven not to be effective.

Minority AIDS Initiative

The AIDS Institute supports increased funding for the Minority AIDS Initiative, which is funded by numerous Federal agencies to address the disproportionate impact that HIV has on communities of color. For fiscal year 2012, we are requesting a total of \$610 million.

Policy Riders

The AIDS Institute is opposed to using the appropriations process as a vehicle to repeal or prevent the implementation of current law or ban funding for certain activities or organizations, such as the Affordable Care Act and syringe exchange programs which are scientifically proven to be effective in the prevention of HIV and Hepatitis.

VIRAL HEPATITIS

The Institute of Medicine (IOM) report Hepatitis and Liver Cancer: A National Strategy for Prevention and Control of Hepatitis B and C outlines recommendations on how the incidence of Hepatitis B and C infections can be decreased. They include increased public awareness campaigns, heightened testing and vaccination programs, continued research, along with improved surveillance. The Administration recently announced the first ever national strategy to eliminate Viral Hepatitis.

In fiscal year 2011, Congress funded CDC's Viral Hepatitis Division at only \$19.8 million. Given the huge impact that Hepatitis B and C have on the health of so many people, and the large treatment costs, and to begin to implement the IOM recommendations and the national strategy, The AIDS Institute urges the Federal Government to make a greater commitment to Hepatitis prevention. For fiscal year 2012, we request a total of \$59.8 million.

The AIDS Institute asks that you give great weight to our testimony as you develop the fiscal year 2012 appropriation bill. Should you have any questions or comments, feel free to contact Carl Schmid, Deputy Executive Director, The AIDS Institute or cschmid@theaidsinstitute.org.

Thank you very much.

PREPARED STATEMENT OF THE ENDOCRINE SOCIETY

The Endocrine Society is pleased to submit the following testimony regarding fiscal year 2012 Federal appropriations for biomedical research, with an emphasis on appropriations for the National Institutes of Health (NIH). The Endocrine Society is the world's largest and most active professional organization of endocrinologists representing more than 14,000 members worldwide. Our organization is dedicated to promoting excellence in research, education, and clinical practice in the field of endocrinology. The Society's membership includes thousands of scientists and clinicians who receive Federal support for their research and, in turn, contribute greatly to the Nation's scientific and healthcare advances.

A half century of sustained investment by the United States Federal Government in biomedical research has dramatically advanced the health and improved the lives of the American people. The NIH specifically has had a significant impact on the United States' global preeminence in research and fostered the development of a biomedical research enterprise that is unrivaled throughout the world. As the world's largest supporter of biomedical research, the NIH competitively awards extramural grants and supports in-house research. However, with the continued decline in real dollars allocated to biomedical research each year by the Federal Government, the opportunities to discover life-changing cures and treatments have already begun to decrease.

Biomedical research funds allocated by the Federal government support both basic and translational research, ensuring that the discoveries made in the laboratory become realistic treatment options for patients suffering from debilitating and life-threatening diseases. Diabetes is a devastating condition that affects an increasingly large number of Americans and requires a large proportion of the Nation's healthcare spending. Almost 26 million people (8.3 percent of the U.S. population) have diabetes, and the estimated cost of diabetes was \$174 billion in 2007.¹

No new diabetes medications would have been developed without federally supported basic and clinical research. The discovery of insulin and the collaborative research effort of basic and clinical scientists eventually led to the approval of a new class of medications for diabetes, essentially the first new treatments of diabetes in

¹ Centers for Disease Control and Prevention. National Diabetes Fact Sheet, 2011.

the past 80 years. Without the continued support of both basic and clinical research in diabetes, these medications would have never been developed. Now, with this broadened portfolio of treatments, it is possible to help most people with diabetes achieve optimal blood sugar control.

Beyond the multitude of health benefits that result from NIH-funded research, national and local economies benefit from the dollars that flow out of NIH into the communities. Researchers in all 50 States and 90 percent of congressional districts receive funding from NIH, and these funds stimulate local economies through salaries and purchase of equipment, laboratory supplies, and vendor services. For instance, for each dollar of taxpayer investment, UCLA generates almost \$15 in economic activity, resulting in a \$9.3 billion impact on the Los Angeles region. The estimated economic impact of Baylor on the surrounding community in Houston is more than \$358 million, generating more than 3,300 jobs.² The governors of 25 States acknowledged the economic impact that NIH-funded research has on their States in an April 2010 letter to House and Senate Budget Committee members. The letter states,

“During a time of recession, investment in biomedical research makes sense because it leads to cures and treatments for debilitating diseases while at the same time generating significant economic activity for local communities throughout the country.”

The Endocrine Society remains deeply concerned about the future of biomedical research in the United States without sustained support from the Federal Government. The Society strongly supports the continued increase in Federal funding for biomedical research in order to provide the additional resources needed to enable American scientists to address the burgeoning scientific opportunities and new health challenges that continue to confront us. The Endocrine Society recommends that NIH receive at least \$35 billion in fiscal year 2012 to ensure the steady and sustainable growth necessary to continue building on the advances made by scientists and physicians during the past decade.

PREPARED STATEMENT OF THE HUMANE SOCIETY OF THE UNITED STATES

On behalf of The Humane Society of the United States (HSUS) and the Humane Society Legislative Fund (HSLF), and our joint membership of over 11 million supporters nationwide, we appreciate the opportunity to provide testimony on our top NIH funding priorities for the Senate Labor, Health and Human Services, Education and Related Agencies Appropriations Subcommittee in fiscal year 2012.

BREEDING OF CHIMPANZEES FOR RESEARCH

The HSUS requests that no Federal funding be appropriated for the breeding of chimpanzees for laboratory research. The basis of our request is as follows:

- The National Center for Research Resources (NCRR) of the National Institutes of Health (NIH), responsible for the oversight and maintenance of federally owned and supported chimpanzees, placed a moratorium on breeding federally owned and supported chimpanzees in 1995, primarily due to the excessive costs of lifetime care of chimpanzees in laboratory settings. NCRR extended the moratorium indefinitely in 2007. As a result, none of the 500 federally owned chimpanzees should have given birth or sired infants since 1995.
- There is evidence, however, that at least one laboratory has used millions of Federal dollars in recent years to support breeding of government owned chimpanzees. There are major financial implications to the Federal Government and taxpayers if this breeding continues. Therefore, we seek to simply reinforce NIH policy and ensure that no laboratory can use funding provided by NIH or any other HHS agency for breeding of government-owned or supported chimpanzees.
- According to records provided by the New Iberia Research Center (NIRC) and the National Institutes of Health 123 infants were born to a federally owned mother and/or federally owned father at NIRC between 2000 and 2009.
- The cost of maintaining chimpanzees in laboratories is exorbitant, up to \$67 per day per chimpanzee; over \$1,000,000 per chimpanzee over an individual's approximately 60-year lifetime. Breeding of additional chimpanzees into laboratories will only perpetuate and increase the burdens on the government in supporting and managing the chimpanzee research colony.

² Federation of American Societies for Experimental Biology. NIH Advocacy Slides: California, Texas.

- The U.S. currently has a surplus of chimpanzees available for use in research due to overzealous breeding for HIV research and subsequent findings that they are a poor HIV model.¹
- Expansion of the chimpanzee population in laboratories only creates more concerns than presently exist about their quality of care—an issue of great public concern.

Background and history

Beginning in 1995, the National Research Council (NRC) confirmed a chimpanzee surplus and recommended a moratorium on breeding of federally owned or supported chimpanzees,¹ which includes nearly all of the approximately 1,000 chimpanzees available for research in the United States. On May 22, 2007 the NCR of NIH indefinitely extended its moratorium on breeding federally-owned and supported chimpanzees. Further, it has also been noted that “a huge number” of chimpanzees are not being used in active research protocols and are therefore “just sitting there.”² If no breeding is allowed, it is projected that the government will have almost no financial responsibility for the chimpanzees it owns within 30 years due to the age of the population—any breeding today will extend this financial burden to 60 years.

There is no justification for breeding of additional chimpanzees for research; therefore lack of Federal funding for breeding will ensure that no breeding of federally owned or supported chimpanzees for research will occur in fiscal year 2012.

Concerns regarding chimpanzee care in laboratories

A nine month undercover investigation by The HSUS at University of Louisiana at Lafayette New Iberia Research Center (NIRC)—the largest chimpanzee laboratory in the world—revealed some chimpanzees living in barren, isolated conditions and documented over 100 alleged violations of the Animal Welfare Act at the facility regarding conditions for and treatment of chimpanzees. The U.S. Department of Agriculture (USDA) and NIH's Office of Laboratory Animal Welfare (OLAW) launched formal investigations into the facility and NIRC paid an \$18,000 stipulation for violations of the Animal Welfare Act.

Aside from the HSUS investigation, inspections conducted by the USDA demonstrate that basic chimpanzee standards are often not being met. Inspection reports for other federally funded chimpanzee facilities have reported violations of the Animal Welfare Act in recent years, including the death of a chimpanzee during improper transport, housing of chimpanzees in less than minimal space requirements, inadequate environmental enhancement, and/or general disrepair of facilities. These problems add further argument against the breeding of even more chimpanzees into this system.

Chimpanzees have often been a poor model for human health research

The scientific community recognizes that chimpanzees are poor models for HIV because chimpanzees do not develop AIDS even after being infected with HIV. Similarly, chimpanzees do not model the course of the human hepatitis C virus yet they continue to be used for this research, adding to the millions of dollars already spent without a sign of a promising vaccine. According to the chimpanzee genome, some of the greatest differences between chimpanzees and humans relate to the immune system,³ calling into question the validity of infectious disease research using chimpanzees.

Ethical and public concerns about chimpanzee research

Chimpanzee research raises serious ethical issues, particularly because of their extremely close similarities to humans in terms of intelligence and emotions. Americans are clearly concerned about these issues: 90 percent believe it is unacceptable to confine chimpanzees individually in government-approved cages (as we documented during our investigation at NIRC); 71 percent believe that chimpanzees who have been in the laboratory for over 10 years should be sent to sanctuary for retire-

¹NRC (National Research Council) (1997) *Chimpanzees in research: strategies for their ethical care, management and use*. National Academies Press: Washington, D.C.

²Cohen, J. (2007) *Biomedical Research: The Endangered Lab Chimp*. Science. 315:450–452.

³The Chimpanzee Sequencing and Analysis Consortium/Mikkelsen, TS, et al., (1 September 2005) Initial sequence of the chimpanzee genome and comparison with the human genome, *Nature* 437, 69–87.

ment⁴; and 54 percent believe that it is unacceptable for chimpanzees to “undergo research which causes them to suffer for human benefit.”⁵

We respectfully request the following bill or committee report language:

“No funds made available in this Act, or any prior Act, may be used for “The Committee directs that no funds provided in this Act be used to support the breeding of federally owned or federally supported chimpanzees for research.”

We appreciate the opportunity to share our views for the Labor, Health and Human Services, Education and Related Agencies Appropriations Act for Fiscal Year 2012. We hope the Committee will be able to accommodate this modest request that will save the government a substantial sum of money, benefit chimpanzees, and allay some concerns of the public at large. Thank you for your consideration.

HIGH THROUGHPUT SCREENING, TOXICITY PATHWAY PROFILING, AND BIOLOGICAL INTERPRETATION OF FINDINGS—NATIONAL INSTITUTES OF HEALTH—OFFICE OF THE DIRECTOR

In 2007, the National Research Council published its report titled “Toxicity Testing in the 21st Century: A Vision and a Strategy.” This report catalyzed collaborative efforts across the research community to focus on developing new, advanced molecular screening methods for use in assessing potential adverse health effects of environmental agents. It is widely recognized that the rapid emergence of omics technologies and other advanced technologies offers great promise to transform toxicology from a discipline largely based on observational outcomes from animal tests as the basis for safety determinations to a discipline that uses knowledge of biological pathways and molecular modes of action to predict hazards and potential risks.

In 2008, NIH, NIEHS and EPA signed a memorandum of understanding⁶ to collaborate with each other to identify and/or develop high throughput screening assays that investigate “toxicity pathways” that contribute to a variety of adverse health outcomes (e.g., from acute oral toxicity to long-term effects like cancer). In addition, the MOU recognized the necessity for these Federal research organizations to work with “acknowledged experts in different disciplines in the international scientific community.” Much progress has been made, including FDA joining the MOU, but there is still a significant amount of research, development and translational science needed to bring this vision forward to where it can be used with confidence for safety determinations by regulatory programs in the government and product stewardship programs in the private sector. In particular, there is a growing need to support research to develop the key science-based interpretation tools which will accelerate using 21st century approaches for predictive risk analysis. We believe the Office of the Director at NIH can play a leadership role for the entire U.S. Government by funding both extramural and intramural research.

We respectfully request the following committee report language, which is supported by The HSUS, HSLF, Procter & Gamble, and the American Chemistry Council.

“The Committee supports the implementation of the National Research Council’s report “Toxicity Testing in the 21st Century: A Vision and a Strategy” to create a new paradigm for chemical risk assessment based on the incorporation of advanced molecular biological and computational methods in lieu of animal toxicity tests within integrated evaluation strategies, and urges the National Institutes of Health to play a leading role by funding a coordinated, long-term program of relevant intramural and extramural research. Current activities at the NIH Chemical Genomics Center, National Institute of Environmental Health Sciences, the Environmental Protection Agency and the Food and Drug Administration show considerable potential and the NIH Director should explore opportunities to augment this effort by identifying additional resources that could be directed to priority research projects. The Director shall report on the NIH funding of and progress on these activities to the Committee commencing September 30, 2012 and annually thereafter.”

⁴2006 poll conducted by the Humane Research Council for Project Release & Restitution for Chimpanzees in laboratories.

⁵2001 poll conducted by Zogby International for the Chimpanzee Collaboratory.

⁶<http://www.genome.gov/pages/newsroom/currentnewsreleases/ntpnccpamou121307finalv2.pdf>.

PREPARED STATEMENT OF THE UNIVERSITY OF VIRGINIA MEDICAL CENTER

Mr. Chairman and Members of the Subcommittee, thank you for the opportunity to submit testimony on behalf of the University of Virginia Medical Center. As members of this committee you have jurisdiction for funding the agencies responsible for the delivery of healthcare in the United States. As a healthcare provider in Virginia and a representative of a major institution responsible for training the healthcare providers of tomorrow, I want to use this opportunity to discuss the vital importance of Federal funding for Graduate Medical Education (GME) in the United States. I urge you to support an increase in the number of appropriately trained physicians in the United States while protecting the integrity and structure of the GME program.

Overview of the University of Virginia Health System

The University of Virginia Health System is an academic medical center composed of the Hospital and its satellite facilities and programs, the School of Medicine, School of Nursing, other allied health programs, and faculty physicians. The University of Virginia Health System plays a critical role in the Nation's healthcare structure as well as the healthcare structure of Virginia. We have multiple key missions: training the next generation of healthcare workers, caring for the sickest patients and the underserved who have nowhere to turn, providing innovative treatments with state-of-the-art technology, and performing medical research. Our key missions are what distinguish us from regular community hospitals.

The University of Virginia Medical Center and its Graduate Medical Education training programs provide an essential bridge for medical school graduates to become well-trained practicing physicians. At the University of Virginia Medical Center, we continuously provide an environment of excellence in which our trainees gain the necessary experience to practice in their specialties in a setting that emphasizes quality and patient safety.

Our training programs have been recognized by the Accreditation Council for Graduate Medical Education for their compliance in meeting the necessary training standards and for their innovative educational techniques. We currently sponsor 68 accredited core specialty and subspecialty training programs. All of our programs are fully accredited, and many have been awarded the maximum accreditation cycle length.

Our programs are well positioned to meet the growing national workforce shortages in primary care (Family Medicine, Internal Medicine including General Medicine, Obstetrics and Gynecology, Pediatrics, and General Surgery), as well as in those specialties where workforce shortages have been identified in the Commonwealth of Virginia (Emergency Medicine, Child and Adolescent Psychiatry).

We have excellent training programs that are well-suited to train physicians who will care for our aging population, including Geriatrics, Palliative and Hospice Medicine, Orthopedic Surgery (including Reconstructive Spine), Endocrinology (Diabetes, Obesity, and Osteoporosis), Cardiology and Cardiothoracic Surgery, Oncology, and Neurology (Alzheimer's Disease).

Funding of Graduate Medical Education

Training of future physicians is a core mission that distinguishes academic medical centers and teaching hospitals like the University of Virginia Medical Center from other healthcare institutions. Congress has recognized the critical role that teaching hospitals play in the training of America's physicians; however, this key endeavor is very expensive. Consequently, Congress has agreed that teaching hospitals should be paid for their increased patient care expenses as well as for their costs associated with GME training programs. This is accomplished through two mechanisms: Direct Graduate Medical Education (DGME) payments and the Indirect Medical Education (IME) adjustment.

The Direct Graduate Medical Education payment (DGME) is a Medicare payment intended to reimburse teaching hospitals directly for resident stipends, the costs of teaching by attending physicians, the expenses incurred with educational classrooms and the administrative costs of the residency program office. Medicare DGME payments are based upon the number of residents and the number of Medicare beneficiaries in the hospital (i.e., it does not cover the entire cost of teaching to the institution.) Currently UVa Medical Center is reimbursed under DGME for approximately 38 percent of the cost of training each resident.

The Indirect Medical Education adjustment (IME) was created in 1983 by Congress. "This adjustment is provided in light of doubts . . . about the ability of the DRG case classification system to account fully for factors such as severity of illness of patients requiring the specialized services and treatment programs provided by teaching institutions and the additional costs associated with the teaching of

residents The adjustment for indirect medical education costs is only a proxy to account for a number of factors which may legitimately increase costs in teaching hospitals.” (House Ways and Means Committee Report, No. 98–25, March 4, 1983 and Senate Finance Committee Report, No. 98–23, March 11, 1983).

The IME adjustment is based on a complex formula that was empirically determined to be related to the ratio of residents to beds (IRB). The hospital’s IME payment is determined by its individual intern/resident-to-bed ratio in a formula established under the Medicare statute. For every Medicare case paid, a teaching hospital receives an additional IME payment, calculated as a percentage add-on to the basic price per case. In 1983, payments added 11.59 percent to each DRG amount for every 10 percent increase in the IRB. The IME adjustment as originally calculated, in conjunction with DGME payments, more satisfactorily reimbursed teaching hospitals for the cost of training the next generation of doctors. However, the Balanced Budget Act of 1997 (BBA) caused the IME adjustment to substantially decline. Over time, Congress has periodically reduced the adjustment—by 30 percent since 1997—to the current 5.5 percent adjustment.

According to the American Association of Medical Colleges (AAMC), the Medicare program annually provides about \$3 billion in DGME payments and \$6 billion in IME payments to nearly 1,100 teaching hospitals. While these payments represent less than 2 percent of total Medicare payments, for teaching hospitals they are extremely important in supporting the mission of training physicians. These payments provide the backbone for our Nation’s healthcare system, and they ultimately contribute to better patient care by providing the support necessary for excellent training programs.

The BBA also capped the number of resident slots that Medicare will support. It limited the number of allopathic and osteopathic resident physicians who may be counted for purpose of calculating IME and DGME reimbursement to the number that the teaching hospital reported on its 1996 Medicare cost report. This cap is preventing academic medical centers and teaching hospitals from expanding the number of residents and fellows even while the Nation continues to suffer a physician shortage. At a time when we should be producing more physicians, especially in the key areas mentioned previously, this outdated rule is thwarting our efforts.

The University of Virginia Medical Center trains more than 750 residents and fellows each year. It is significantly over its Medicare limit or cap for training slots. For purposes of Direct Graduate Medical Education, the University of Virginia’s cap is 538 residents, and it is 121 positions over its cap; for purposes of Indirect Graduate Medical Education, the University of Virginia’s cap is 508 residents, and it is 131 positions over its cap. The cost of training a resident is approximately \$100,000 per year, thus, the University of Virginia Medical Center is spending about \$12,100,000 per year on resident positions over the cap.

Graduate Medical Education training helps ensure that healthcare delivery in the United States continues to be the highest quality. The additional costs incurred at teaching hospitals for the training of tomorrow’s doctors are real and should be reimbursed at a level commensurate with the expense. Without specific appropriate reimbursement from Medicare, teaching hospitals will run deficit budgets and be forced to cut the very programs that differentiate them and allow them to provide the best and most innovative care.

Challenges Facing Graduate Medical Education

Recently, the National Commission on Fiscal Responsibility and Reform recommended reducing the IME adjustment from 5.5 percent to 2.2 percent annually, which represents an approximate two-thirds cut in the IME payment. The potential loss of approximately two-thirds support from the Federal Government would severely compromise the ability of the University of Virginia Medical Center, and other academic medical centers, to fund this crucial educational mission. The estimated impact of this reduction on the University of Virginia Medical Center is approximately \$26,700,000 per year.

Although we recognize the importance of a balanced Federal budget and the need to control healthcare spending, reducing the funds available for training future physicians will lead to a severe lack of access to healthcare in the near future. This will occur at the very time that hospitals are being asked to expand access to care.

For example, the Patient Protection and Affordable Care Act (i.e., the healthcare reform law) will provide health insurance coverage to 32 million more Americans; however, health insurance does not guarantee timely access to care. There must be a well trained workforce to care for the additional patients to ensure that implementation of the new healthcare reform law is successful. Unfortunately, the United States is already experiencing a shortage of physicians. As healthcare reform is fully implemented and the population of the United States continues to age, the shortage

of physicians is expected to worsen. By 2020 the demand for physicians will significantly outweigh the supply. According to the AAMC's Center for Workforce Studies, by 2020 there will be a shortage of 45,000 primary care physicians, and a shortage of 46,000 surgeons and medical specialists.

Only 700 Medicare-funded training slots were awarded during the most recent reallocation authorized by the healthcare reform law. Most teaching hospitals, including the University of Virginia, did not receive any additional Medicare-funded residency slots. Unless the cap is increased or lifted, it is expected that there will be more medical school graduates than residency positions in the near future. Indeed, in its April GME e-letter (<http://www.ama-assn.org/resources/doc/med-ed-products/gmee-04-2011.pdf>) the American Medical Association stated that we may have already reached the point where U.S. medical school graduates are not able to find a residency position because there are now more graduates than available GME slots.

Specifically, the University of Virginia School of Medicine, along with dozens of medical schools nationally, has increased class size to meet the needs of the impending workforce shortages. However, medical students looking to join a residency program have begun to face a significant bottleneck after graduation. While institutions like the University of Virginia are graduating exceptional medical students, the University of Virginia Medical Center can only accept a finite number Medicare-funded residency positions due to the cap. Thus, the shortage of open residency positions for medical students creates another barrier to the supply of well-trained physicians.

To address the severe doctor shortage crisis facing the United States and to ensure that there is a well-trained healthcare workforce to successfully care and treat the increasing number of patients in the future, it is critical that Congress support Graduate Medical Education by increasing the number of resident slots available for medical students, and continue to invest in Graduate Medical Education. I respectfully request that this committee do everything within its jurisdiction to achieve these important goals.

PREPARED STATEMENT OF THE TRI-COUNCIL FOR NURSING

The Tri-Council for Nursing, comprised of the American Association of Colleges of Nursing, the American Nurses Association, the American Organization of Nurse Executives, and the National League for Nursing, respectfully request \$313.075 for the Nursing Workforce Development programs authorized under Title VIII of the Public Health Service Act (42 U.S.C. 296 et seq.) in fiscal year 2012. This is the amount requested in the recommended funding levels for the President's fiscal year 2012 budget.

The Tri-Council is a long-standing nursing alliance focused on leadership and excellence in the nursing profession. This marks the 13th year of the nurse and nurse faculty shortages which have eroded the ability of the nursing profession to provide the highest quality of care that all patients rightfully desire and morally deserve. As the Nation looks toward restructuring the healthcare system by focusing on expanding access, decreasing cost, and improving quality, a significant investment must be made in strengthening the nursing workforce, a profession which The U.S. Bureau of Labor Statistics expects a 22 percent growth in employment through 2018.

PREPARED STATEMENT OF THE UNITED NEGRO COLLEGE FUND

Mr. Chairman and distinguished Members of the subcommittee, I am Dr. Michael L. Lomax, President and CEO of UNCF—the United Negro College Fund. I want to thank you for allowing me to submit funding recommendations and priorities relevant to the fiscal year 12 Labor-HHS-Education Appropriations bill.

Statistically, HBCUs graduate a preponderant share of all black Americans receiving postsecondary degrees. While comprising only 3 percent of the Nation's 4,197 institutions of higher learning, the 106 HBCUs are responsible for producing approximately 25 percent of all bachelor's degrees, 10 percent of all master's degrees and 26 percent of all first professional degrees earned by African Americans annually.

UNCF institutions are a critical component and significant subset of the larger community of HBCUs. Specifically, UNCF is the national fundraising and advocacy representative for 38 private historically black colleges and universities. There are more than 350,000 persons who are counted as alumni of UNCF member colleges and universities. Our alumni include persons such as Rev. Dr. Martin Luther King, Jr., Brown University President Dr. Ruth Simmons, three former surgeon generals,

numerous current Members of Congress and a host of noted authors, poets, attorneys, professors and philanthropists.

UNCF—the Nation’s oldest and most successful minority higher education assistance organization—fulfills its primary goal by increasing opportunities for access to higher education. During its 66-year existence, UNCF has raised more than \$3 billion to support its historically black college and university member institutions and administered nearly 400 programs, including scholarships, mentoring programs, summer enrichment, study abroad, curriculum, faculty, and leadership development. Today, UNCF supports more than 65,000 students at over 900 colleges and universities across the country.

We recognize that working with the Administration and Congress will continue to be particularly challenging in a budget-constrained environment where more diverse students with unique academic and familial circumstances are dependent upon need-based aid. The face of our Nation is changing and nowhere is the change more evident than in education. Compared with the last century, we are increasingly changing with more of us being born in other nations, speaking other languages and carrying different cultures. Minority

populations are growing more quickly than the U.S. population as a whole. In keeping with this, UNCF continues to endorse the following policies and positions as the focal point of its legislative agenda for fiscal year 2012. These recommendations continue a basic commitment to enrolling, nurturing, and graduating students, some of whom lack the social, educational, and financial advantages of other college bound populations. This agenda reflects what is needed to level the playing field for both UNCF member schools and students as we continue to pursue educational excellence.

The following fiscal year 2012 programs are of particular relevance and importance to UNCF.

Title III, Part B, Strengthening Historically Black Colleges and Universities—\$267 million (Section 323)

Because of its flexibility, this program is the fundamental source of institutional assistance for HBCUs and is used to support strategic planning initiatives, academic enhancements, administrative and fiscal management, student services, physical plant improvements, and general institutional development.

The current level of funding to Title III, Part B must be maintained in order to continue to enhance and sustain the quality of HBCUs, and to meet the national challenges associated with global competitiveness, job creation and changing demographics. For fiscal year 2012, UNCF requests \$267 million to support Section 323.

Title III, Part D, HBCU Capital Financing Program—a minimum of \$20.58 million, plus increase the statutory cap to at least \$1.7 billion. Bill language is needed to make funding available to institutions that have a need but fall into a category that has exhausted resources within the current cap of \$1.1 billion.

Funded through Title III, Part D of the Higher Education Act, the HBCU Capital Financing Program is intended to provide low-interest capital financing loans to historically disadvantaged institutions throughout the HBCU community. In light of economic hardships and challenges confronting several of our member institutions, UNCF has worked with national stakeholders, officials at the Department of Education, and Congressional leadership to propose a comprehensive revision of the capital financing provisions.

For fiscal year 2012, UNCF requests at least \$20.58 million to allow the Secretary to support the administration of additional loans through the Capital Financing Program. Further, we request the assistance of Federal leaders in working with the HBCU Capital Financing Board to ensure that recommendations made to Congress will promote increased participation within the program among all eligible institutions.

The Hawkins Centers of Excellence Program—\$40 million

Under this budget proposal, the Administration proposes giving grants to minority-serving institutions to prepare teachers by providing extensive training, creating a system for tracking program graduates and raising exit standards. The Centers are named after the recently deceased Augustus F. Hawkins in honor of his historic leadership as a champion for expanding education as well as job opportunity.

For fiscal year 2012, UNCF requests \$40 million to implement the Hawkins Centers of Excellence Program. This program would help expand the pool of effective minority teachers thus working to close the achievement gap for minority students.

Pell Grants Program—\$5,550 (current maximum reward)

This program assists so many deserving students in getting into college. As college costs increase, the amount of jobs available to solely high school graduates is rapidly decreasing. It is imperative to preserve the maximum award of \$5,550 and continue to fund Pell at the appropriate level. The budget would call for a cut of \$100 billion in Pell grants over 10 years, paid for by eliminating the “Two Pell” benefits and the in-school interest subsidy for graduate and professional student loans.

For fiscal year 2012, UNCF requests the current maximum awards of \$5,550 to continue the support of the Pell Grants Program. Maintaining the maximum Pell award is critical to ensure that the growing pool of first generation and low income college students are provided much needed financial support to access higher education and minimize the burden of costly education loans.

UNCF and our member schools have, among them, many years of experience in making the dream of a college education a reality for low-income students and the colleges they attend. My staff and I, as well as the presidents of our member schools, stand ready to continue to work closely with your committee to formulate and craft a plan that will work for all the young people who are seek and deserve college education.

PREPARED STATEMENT OF THE UNITED NETWORK FOR ORGAN SHARING

Highlighting the urgent need to address the ever-growing waiting list for organs for transplantation and the number of people that die every day just waiting for an organ, by strengthening programs at HRSA, the National Institutes of Health and within the Office of the Secretary.

Mr. Chairman and Members of the Subcommittee, thank you for giving the United Network for Organ Sharing (UNOS) the opportunity to provide testimony as the Subcommittee begins to consider funding priorities for fiscal year 2012. My name is Mary Ellison and I am the Acting Executive Director of UNOS, the organization with the Federal contract to coordinate the Nation’s organ transplant system, providing vital services to meet the needs of men, women and children awaiting life-saving organ transplants. Based in Richmond, Virginia, UNOS is a private, non-profit membership organization. UNOS members encompass every transplant hospital, tissue matching laboratory and organ procurement organization in the United States, as well as voluntary health and professional societies, ethicists, transplant patients and organ donor advocates.

Transplantation has saved and enhanced the lives of more than 450,000 people in the United States. It is the leading form of treatment for many forms of end-stage organ failure. With this success, however, has come increasing demand for donated organs. Living donation (transplanting all or part of an organ from a living person) has increased dramatically in the last few years, helping increase the number of transplants performed. In addition, UNOS has enacted a number of policies to encourage more efficient use of available organs, such as “splitting” livers from deceased donors to allow two recipients to be transplanted. The only long-term solution to the organ shortage, however, is for more people to agree to become organ donors. UNOS works closely with medical professionals to increase their understanding and support of the organ donation process.

Mr. Chairman, as you know the primary Federal agency with jurisdiction over organ transplantation issues is the Health Resources Services Administration. However, as we will describe below, the Office of the Secretary and NIH also have important roles to play to help people in need of an organ transplant.

Health Resources Services Administration

Even with advances in the use of living liver donors, the increase in the demand for organs needed for transplantation will continue to exceed the number available. The need to increase the rate of organ donation is critical. On April 11, 2011 there were 110,676 men, women and children on the national transplantation waiting list. Last year an average of 74 patients were transplanted each day; however a daily average of 18 patients died because the organ they needed did not become available in time to save them. HRSA’s Division of Transplantation has a proven track record of successfully increasing the rate of organ donation with limited resources.

Recognizing the importance of this issue, Congress passed, and the President signed, the Organ Donation and Recovery Improvement Act of 2004 (Public Law 108–216) authorizing an increase of \$25 million for organ donation activities in the first year, and such sums as necessary in following years, and yet, it was only last year that additional funding of \$1 million has been provided to implement this legislation. To address these needs, UNOS recommends that the Division of Transplan-

tation receive a \$2 million increase in fiscal year 2012, to allow the Division to more aggressively pursue program efforts to increase the supply of organs available for transplantation.

In addition, the shortage of organs for donation can be positively impacted by healthcare professionals, particularly physicians, nurse, and physician assistants that are frequently the first to identify and refer a potential donor. These professionals also have an established relationship with the family members that weigh the option to donate their loved one's organs. In order to improve the knowledge and skills of the several key health professions, UNOS requests funding to develop curriculum and continuing medical education programs for targeted health professions. To launch a new 5 year effort to improve the competency of health professionals to help meet the goal of increasing the number of organs available for transplantation \$450,000 is requested for the United Network for Organ Sharing (UNOS) to be made available from within the base funding of the Division of Health Professions based on the authority provided in Section 765 of Title VII to improve the workforce.

Office of the Secretary

On March 3, 2008 the Department published a request for information in the Federal Register to gather information to assist the Department to determine whether it should engage in a rulemaking with respect to vascularized composite allografts (VCAs). Three years later, the Department still has not finalized this decision. As it currently stands, the Food and Drug Administration has jurisdiction over VCA transplants, as they are currently defined as human tissue. However, as the numbers of these transplants are growing, finalizing the decisions associated with this issue and allowing HRSA's Division of Transplantation to have jurisdiction over VCA's will permit this category of transplants to benefit from the policy oversight and expertise of the Organ Procurement Transplant Network (OPTN).

Worldwide there have been more than two dozen limb transplants, a growing number of transplants of portions of the face, and a small number of transplants of other anatomical parts. Although the body parts vary significantly, they share important common characteristics with organ transplantation. As with organs, the VCA graft is subject to damage or death from the lack of blood flow and the need for revascularization is done through a surgical reconnection of blood vessels. Additionally, all the expertise and skills of healthcare professional trained to work with families, individuals and hospitals in the organ donation and procurement process are also needed in the donation and procurement of VCAs. All of these vital activities are already performed and overseen by the organ transplant community. Further, for 25 years the OPTN has overseen the processes and crafted policies to regulate them under Federal contract. It therefore seems logical, efficient and will serve the best interests of patients and the Nation's transplant system to bring VCAs under the umbrella of the OPTN.

UNOS urges the Office of the Secretary to take action on this decision, and issue the rule and begin the necessary process of amending the definition of human organs. This is especially critical given the recent activities of private entities that, lacking Federal leadership, have begun taking the necessary steps to form registries for VCAs. As we learned over 20 years ago when the OPTN was established, it is crucial to have Government oversight over registries such as this in order to establish fair and ethical distribution of body parts.

National Institutes of Health

Mr. Chairman, as you know, the National Institute of Allergy and Infectious Diseases has jurisdiction over transplantation research at the NIH. Recent research funded by NIAID has resulted in the development of desensitization protocols related to kidney transplantation that have shown remarkable progress in helping allow the most vulnerable of patients live with a transplant. Up to 30 percent of the people on the renal transplant waiting list—without special intervention—will likely never have the chance to receive a transplant due to an inability to find a compatible donor. These patients have become “sensitized” to human antigens (HLA) through pregnancy, transfusions, or prior transplants and therefore must wait significantly longer for a compatible donor. This added time on the wait list directly increases both their disease-related complications and mortality.

To improve access to transplantation for most these broadly sensitized patients, desensitization protocols have evolved to decrease the breadth and strength of their antibodies. Survival rates are excellent, equaling or exceeding the rates for kidney transplantation generally. It is reasonable to estimate that if these protocols were confirmed to be as safe and effective as early peer reviewed data has suggested, a large number of these long-suffering people could be successfully transplanted and removed from the waiting list each year. UNOS recommends that NIAID support

a multi-center initiative with a companion data collection and analysis center to facilitate the use of this protocol at an increasing number of transplant centers across the country.

Summary and Conclusion

Mr. Chairman, again we wish to thank the Subcommittee for the opportunity to submit testimony and for your leadership in these difficult times. While UNOS recognizes the demands on our Nation's resources, we believe the ever-growing waiting list for organs for transplantation, and the number of people that die every day just waiting for an organ, continue to justify higher funding levels for HRSA's Division of Transplantation.

In conclusion, we specifically request the following for fiscal year 2012:

- A \$2 million increase for HRSA's Division of Transplantation;
- \$450,000 from within the base funding of the Division of Health Professions to develop curriculum and continuing medical education programs for targeted health professions;
- Report language urging the Office of the Secretary to finalize a decision to amend the definition of human organs to include vascularized composite allografts, and allow this category to come under the umbrella of the OPTN; and
- Report language within the National Institute of Allergy and Infectious Disease to support a multi-center initiative focused on "desensitizing" patients previously found incompatible with most human organs.

PREPARED STATEMENT OF THE UNITED TRIBES TECHNICAL COLLEGE

For 42 years, United Tribes Technical College (UTTC) has provided postsecondary career and technical education, job training and family services to some of the most impoverished, high risk Indian students from throughout the Nation. We are governed by the five tribes located wholly or in part in North Dakota. We are not part of the North Dakota State college system and do not have a tax base or State-appropriated funds on which to rely. We have consistently had excellent retention and placement rates and are a fully accredited institution. Section 117 Carl Perkins Act funds represent about half of our operating budget and provide for our core instructional programs. The requests of the United Tribes Technical College Board for fiscal year 2012 is for the following authorized Department of Education programs:

- \$10 million for base funding authorized under Section 117 of the Carl Perkins Act for the Tribally Controlled Postsecondary Career and Technical Institutions program (20 U.S.C. Section 2327). This is \$1.8 million above the fiscal year 2010 level and the President's requests for fiscal years 2011 and 2012. These funds are awarded competitively and are distributed via formula.
- \$30 million as requested by the American Indian Higher Education Consortium for Title III-A (Section 316) of the Higher Education Act (Strengthening Institutions program).
- Maintain Pell Grants at the \$5,550 maximum award level.

AUTHORIZATION

United Tribes Technical College began operations in 1969. We realized that in order to more effectively address the unique needs of Indian people to acquire the academic knowledge and skills necessary to enter the workforce we needed to expand our curricula and services. We were scraping by with small amounts of money from the Bureau of Indian Affairs, and so decided to work for an authorization in the Department of Education. That came about in 1990 when the Carl Perkins Act was reauthorized and it included specific authorization for what is now called the Tribally Controlled Postsecondary Career and Technical Institutions program (Section 117). The Perkins Act has been reauthorized twice since then—in 1998 and in 2006, with Congress each time continuing the Section 117 Perkins program.

Some Important Facts About United Tribes Technical College.—We have:

- A dedication to providing an educational setting that takes a holistic approach toward the full spectrum of student needs—educational, cultural, necessary life skills—thus enhancing chances for success.
- Services including campus security, a Child Development Center, a family literacy program, a wellness center, area transportation, a K–8 elementary school, tutoring, counseling, and family and single student housing.
- A semester completion rate of 80–90 percent.
- A graduate placement rate of 94 percent (placement into jobs and higher education).

- A projected return on Federal investment of 20–1 (2005 study).
- Highest level of accreditation from the North Central Association of Colleges and Schools.
- Over 30 percent of our graduates move on to 4-year or advanced degree institutions.
- A student body representing 87 tribes who come mostly from high-poverty, high unemployment tribal nations in the Great Plains; many students have children or dependents.
- 81 percent of undergraduate students receive Pell Grants, the highest percentage of Pell Grant recipients of any North Dakota college.
- 21 2-year degree programs, eight 1-year certificates, and 3 bachelor degree programs pending final accreditation this spring.
- An expanding curricula to meet job-training needs for growing fields including law enforcement, energy auditing and health information management. We have also broadened our online program offerings.
- A critical role in the regional economy. Our presence brings \$31.8 million annually to the economy of the Bismarck region.
- A workforce of over 300 people.
- An award-winning annual powwow which last year had participants from 70+ tribes, featuring over 1,500 dancers and drummers, and drawing over 20,000 spectators. We annually feature indigenous dance groups from other countries.

FUNDING REQUESTS

Section 117 Perkins Base Funding.—Funds requested under Section 117 of the Perkins Act above the fiscal year 2010 level are needed to: (1) maintain 100 year-old education buildings and 50 year-old housing stock for students; (2) upgrade technology capabilities; (3) provide adequate salaries for faculty and staff (who have not received a cost of living increase for the past 2 years and who are in the bottom quartile of salary for comparable positions elsewhere); and (4) fund program and curriculum improvements, including at least three 4-year degree programs.

Acquisition of additional base funding is critical as UTTC has more than tripled its number of students within the past 8 years while actual base funding, including Interior Department funding, have not increased commensurately (increased from \$6 million to \$8 million for the two programs combined). Our Perkins funding provides a base level of support while allowing the college to compete for desperately needed discretionary contracts and grants leading to additional resources annually for the college's programs and support services.

Title III–A (Section 316) Strengthening Institutions.—We support Title III–A funding for tribal colleges. Among its statutorily allowable uses is facility construction and maintenance. We are constantly in need of additional student housing, including family housing. We work hard to cobble together various sources for housing construction. We would like to educate more students but lack of housing has at times limited the admission of new students. With the completion this past year of a new Science and Math building on our South Campus on land acquired with a private grant, we urgently need housing for up to 150 students, many of whom have families. New housing on the South Campus could also accommodate those persons we expect to enroll in a new police training program.

While UTTC has constructed three housing facilities using a variety of sources in the past 20 years, approximately 50 percent of students are housed in the 100-year-old buildings of the old Fort Abraham Lincoln, as well as in duplexes and single family dwellings that were donated to UTTC by the Federal Government along with the land and Fort buildings in 1973. These buildings require major rehabilitation. New buildings for housing are actually cheaper than trying to rehabilitate the old buildings that now house students.

Pell Grants.—We support maintaining the Pell Grant maximum amount to at least a level of \$5,550. As mentioned above, 81 percent of our students are Pell Grant-eligible. This program makes all the difference in the world of whether these students can attend college. We also support the continuation of appropriations to fund two scheduled award years per year, as this has helped many of our students shorten the time to obtain their degrees.

GOVERNMENT ACCOUNTABILITY OFFICE REPORT

As you know, the Government Accountability Office (GAO) in March of this year issued two reports regarding Federal programs which may have similar or overlapping services or objectives (GAO–11–318SP of March 1 and GAO–11–474R of March 18). Funding from the Bureau of Indian Education (BIE) and the Department of Education's Perkins Act for Tribally Controlled Postsecondary Career and Technical

Institutions were among the programs listed in the supplemental report of March 18. The GAO did not recommend defunding these or other programs; in some cases consolidation or better coordination of programs was recommended to save administrative costs. We are not in disagreement about possible consolidation or coordination of the administration of these funding sources so long as funds are not reduced.

Perkins funds represent about 46 percent of UTTC's core operating budget. The Perkins funds supplement, but do not duplicate, the BIE funds. It takes both sources of funding to frugally maintain the institution. In fact, even these combined sources do not provide the resources necessary to operate and maintain the college. Therefore, UTTC actively seeks alternative funding to assist with academic programming, deferred maintenance of its physical plant and scholarship assistance, among other things.

Second, as mentioned, UTTC and other tribally chartered colleges are not part of State educational systems and do not receive State-appropriated general operational funds for their Indian students. The need for postsecondary career and technical education in Indian Country is so great and the funding so small, that there is little chance for duplicative funding.

There are only two institutions targeting American Indian/Alaska Native career and technical education and training at the postsecondary level—United Tribes Technical College and Navajo Technical College. Combined, these institutions received less than \$15 million in fiscal year 2010 Federal funds (\$8 million from Perkins; \$7 million from the BIE). That is not an excessive amount of money for two campus-based institutions which offer a broad (and expanding) array of programs geared toward the educational and cultural needs of their students and toward job-producing skills.

UTTC offers services that are catered to the needs of our students, many of whom are first generation college attendees and many of whom come to us needing remedial education and services to address the sociobehavioral, socioeconomic, and academic characteristics that pose problems. Our students disproportionately possess more high risk characteristics than other student populations. We also provide services for the children and dependents of our students. Although BIE and Section 117 funds do not pay for remedial education services, UTTC must make this investment with our student population through other sources of funding to ensure they succeed at the postsecondary level.

Federal funding for American Indian/Alaska Native employment and training is barely 1 percent of the annual Federal employment and training budget but has an enormous impact on the people and communities it serves.

Perkins funds are central to the viability of our core postsecondary educational programs. Very little of the other funds we receive may be used for core career and technical educational programs; they are competitive, often one-time supplemental funds which help us provide the services our students need to be successful. We cannot continue operating without Carl Perkins funds. Thank you for your consideration of our requests.

PREPARED STATEMENT OF THE U.S. HEREDITARY ANGIOEDEMA ASSOCIATION

Thank you for the opportunity to present the views of the U.S. Hereditary Angioedema Association (USHAEA) regarding the importance of hereditary angioedema (HAE) research.

USHAEA was founded in 1999 with the express purpose of helping those living with HAE and their families to live healthy lives, provide support, and find a cure. The Association provides patient services to those living with HAE, including referrals to knowledgeable healthcare providers and information on the disease. USHAEA also provides research funding to scientific investigators to increase the knowledge base on HAE. Additionally, USHAEA also provides research materials and forums to educate the patients and their families, healthcare providers, and the general public on HAE. Finally, USHAEA acts as a voice for those living with HAE to the world at large.

HAE is caused by a genetic defect which controls C1-Inhibitor blood protein, causing an inability to regulate complex biochemical interactions in blood-based systems involved in disease fighting, inflammatory response, and coagulation. Episodes of HAE are characterized by swelling in the body including the hands, feet, gastrointestinal tract, face, and airway. During an episode, HAE patients experience abdominal pain, nausea, vomiting, and airway swelling, which can lead to asphyxiation. Episodes are often caused by infections, minor injuries or dental procedures, emotional or mental stress, and certain hormonal or blood medications. HAE impacts approximately 1 in 10,000 to 1 in 50,000, making proper diagnosis difficult.

Many of the initial HAE episodes occur in children and adolescents. In families where one parent has HAE, there is a 50 percent probability that their children will inherit this condition. HAE has an annual cost which can exceed \$500,000 per year per patient in addition to the human and economic burdens associated with the disease.

Research Through the National Institutes of Health

In years past, HAE research was conducted at the National Institutes of Health (NIH) through the National Institute of Allergy and Infectious Diseases, the National Institute of Neurological Disorders and Stroke, the National Heart, Lung, and Blood Institute, the National Institute of Child Health and Human Development, National Center for Research Resources, and the National Institute on Diabetes and Digestive and Kidney Diseases. However, NIH has not engaged in any basic or clinical research on HAE since 2009, nor is there any Federal research as it relates to HAE. As a rare disease, HAE stands to benefit from recent NIH commitments such as the Cures Acceleration Network and the Therapeutics for Rare and Neglected Diseases program, as well coordination with the Office of Rare Diseases Research.

In order to enable research to resume on HAE, it is vital that NIH receive increased support in fiscal year 2012. USHAEA recommends an overall funding level of \$35 billion for NIH in fiscal year 2012 and the inclusion of recommendations emphasizing the importance of HAE research.

Thank you for the opportunity to present the view of the HAE community.

PREPARED STATEMENT OF YWCA USA

Thank you Chairman Harkin, Ranking Member Shelby and members of the Subcommittee for the opportunity to submit testimony. My name is Gloria Lau, and I am the Chief Executive Officer of the YWCA USA. As Congress works on the appropriations and priorities for the fiscal year 2012 Federal budget, I am here to speak about one priority in particular under the jurisdiction of this subcommittee: the critical need for childcare for women and families.

The YWCA USA is a national not-for-profit (501(c)(3)) membership organization committed to social service, advocacy, education, leadership development, economic empowerment and racial justice. The YWCA is dedicated to eliminating racism, empowering women and promoting peace, justice, freedom and dignity for all. We represent more than 2 million women and girls, and we can be found in many communities in the United States. With nearly 300 local associations nationwide, we serve thousands of women, girls, and their families annually through a variety of programs; including violence prevention and recovery programs, housing programs, job training and employment programs, childcare and early education programs, and more. Our clients include women and girls from all walks of life, including those escaping violence, low-income women and children, women veterans, elderly women, disabled women, and homeless women and their families.

The YWCA is one of the largest providers of childcare in the United States. Many of our associations provide accessible, affordable, and high-quality childcare services to working families nationwide. In one example close to the Nation's Capital, the YWCA of Baltimore, Maryland, an association committed to providing quality childcare for all children, serves more than 600 children annually. At this and other YWCA childcare centers, the day is designed to meet the developmental needs and the interests of each child. Each day includes a variety of intellectual, physical, social, emotional, and creative activities as well as opportunities to interact with other children and adults. In another example, the childcare program at the YWCA in Lawrence, Massachusetts has been ranked in the top 10 childcare programs in Massachusetts by Root Cause, an organization that encourages social innovation and helps corporations source exceptional programs. Starting with this program, many children join YWCA as infants or toddlers and stay in programming into their teen years, which provides continuity of care for children and siblings. Finally, at the YWCA Greater Cincinnati, the State of Ohio has recognized that association's programs with a three-star rating for having met all State benchmarks for quality. If members of the Subcommittee wish, we can provide you far more examples of how YWCAs are providing quality childcare critical to the country's children and their families.

As a major provider of childcare throughout the United States, the YWCA is a strong supporter of the Childcare Development Block Grant (CCDBG). Across the country, YWCAs use CCDBG funding for a variety of programs, including childcare for infants and toddlers, and before- and after-school care for children in school.

CCDBG also provides childcare subsidies for low-income and moderate-income YWCA clients who attend our job training programs, live in our housing facilities, or are served by domestic violence and sexual assault programs. Every day, in communities across this country, we witness the important role CCDBG plays in helping parents find and keep employment and in helping children learn and grow.

Because of our strong support for the CCDBG, the YWCA asks the Subcommittee to concur—at a minimum—with the President's fiscal year 2012 funding request, which includes \$2.9 billion for the CCDBG in the Department of Health and Human Services. This call for support comes directly from communities across the country, as local YWCA associations surveyed in December 2010 identified this vital block grant as one of their most critical funding sources. We also support Head Start and Early Head Start, which the President has requested for fiscal year 2012 at \$8.1 billion and which rounds out the continuum of services for young children and their families.

The YWCA wholeheartedly supports the core purpose of the CCDBG, which is to help make quality childcare affordable for low-income and moderate-income women and families, through block grant funding for States and tribes. CCDBG is not a cookie-cutter/one size fits all program: it provides States flexibility in developing childcare programs and policies most appropriate to fulfill the needs of children and parents within that State, as well as empowers working parents to make their own decisions on childcare services that best suit their family's needs. CCDBG helps keep parents educated about their childcare options through consumer information so that they can make informed choices, while helping them to achieve economic stability and independence.

The need is simple—if working parents do not have access to affordable, quality childcare for their children, they cannot be full contributors to the economy. Each week, more than 11 million children under 5 years of age are in some type of childcare setting¹.

The problem is: childcare costs are high—compared to family income and household expenses—and they are growing. The average amount parents paid for full-time care for an infant in a center ranged from more than \$4,560 in Mississippi to more than \$18,773 a year in Massachusetts (\$5,356 in Alabama and \$8,273 a year in Iowa)². Furthermore, the average center-based childcare fees for an infant exceeded the average annual amount that families spent on food in every region of the country. In addition, childcare fees per month for two children of any age exceeded the median monthly amount for rent, and were nearly as high, or even higher than, the average monthly mortgage payment in every State. YWCAs offer quality childcare at a low cost to the families they serve, but many of them would have to turn people away or simply end programs without State CCDBG funds. This, in turn, would result in parents losing childcare which would impact their ability to work and could possibly result in children being placed in unfit or unsafe childcare situations, further impacting their ability to learn and grow.

Investments in early education are critical to our effort to build a smarter and stronger country, even in economic times that call for budget-cutting measures. Quality, affordable early childhood care and education result in positive outcomes for children, such as preparing them for school and helping parents find and keep jobs. It also benefits taxpayers and enhances economic vitality. Research³—by Nobel Prize-winners and Federal Reserve economists, in economic studies in dozens of States and counties, and in longitudinal studies spanning 40 years—demonstrate that return on public investment in high quality childhood education is substantial.

Specifically, it was found that, in the short term, quality, affordable childcare provides significant return as an industry: employing nearly 3 million people nationwide; providing employees wages to spend, pay taxes and purchase goods and services; and enabling employers to attract and retain employees and increase productivity. In the long term, quality, affordable childcare has been found to result in lower costs for remedial and special education and grade repetition; higher rates of completing school and building skills; improved job preparedness and ability to meet

¹U.S. Census Bureau, 2006–2008 American Community Survey. U.S. Census Bureau. (2008, March). Who's minding the kids? Childcare arrangements: Spring 2005: Detailed tables. Retrieved April 19, 2010, from <http://www.census.gov/population/www/socdemo/child/ppl-2005.html>.

²*Parents and the High Cost of Childcare: 2010 Update* from the National Association of Childcare Resource and Referral Agencies (provides average costs of childcare for infants, 4-year-olds, and school-age children in centers and family childcare homes in every State), <http://www.naccrra.org/publications/naccrra-publications/parents-and-the-high-cost-of-child-care.php>.

³Early Childhood Education for All: A Wise Investment. U.S. Census Bureau (2005, April). "The Economic Impacts of Childcare and Early Education: Financing Solutions for the Future;" a conference sponsored by Legal Momentum's Family Initiative and the MIT Workplace Center. Retrieved April 7, 2011, from <http://web.mit.edu/workplacecenter/docs/Fall%20Report.pdf>.

future labor force demands; and higher incomes and tax payments from those who complete school.

As stated in a letter to both of you and the Chair and Ranking Member of the Senate Appropriations Committee signed by 17 Senators on February 24, 2011, “noted economists agree that investing in early childhood education is fiscally responsible because it yields a tremendous return on investment, ranging from \$3 to \$17 for every dollar invested.” The letter goes on to state, “Given these gaps and the importance of early learning to our country’s economic success, the American Recovery and Reinvestment Act (ARRA) included a prudent and essential expansion of these programs. We strongly believe that Congress must build on this progress, not reverse it.”⁴ The YWCA strongly believes that as Congress focuses on effective and efficient uses of Federal funds, Congress should not overlook the benefits of allocating Federal dollars toward childcare and early education programs, particularly to cultivate younger generations.

Congress and several Presidential administrations have historically shown strong bipartisan support for CCDBG. Even so, for the 21 years CCDBG has been in existence, the program has always been underfunded and supply has never met demand. Even before the current economic downturn, it was estimated that only 1 in every 7 children who were eligible for CCDBG received assistance. It was also not uncommon for children and their families to be put on waiting lists, to see their assistance cut, or to see it eliminated altogether. The economic downturn has exacerbated this already alarming situation as States continue to cut back social service programs more than they had been scaled back, prior to economic collapse.

In a positive response, as referred to in the joint Senate letter to the Appropriations Committee referenced earlier, the ARRA made a major, \$2 billion investment in childcare. The significant increase for CCDBG included in the President’s fiscal year 2012 budget request would allow children served by ARRA funding to continue receiving services. This level of funding would allow 1.7 million children to receive childcare assistance, an increase of 220,000 children—at great relief to their working parents. The \$1.3 billion increase would translate into an increase of \$800 million for discretionary funding (which does not require a State match) and \$500 million for mandatory funding (which requires a State match. Approving the President’s proposed level of funding will ensure positive impact to the working women and families that are an essential part of our Nation’s economic recovery.

The need for and importance of investments in childcare and early childhood education, including CCDBG funding, to the viability of our country is now greater than ever. In addition, the current budget crises facing States across this Nation illustrate why Federal investments in quality childcare and early education programs are both necessary and vital. For example, the National Women’s Law Center (NWLC) reported on April 7, 2011⁵, States have begun to cut back on childcare assistance:

“Until recently, most States have managed to maintain their childcare assistance programs, largely thanks to an additional \$2 billion in Childcare Development Block Grant (CCDBG) funding for fiscal year 2009 and fiscal year 2010 from the American Recovery and Reinvestment Act (ARRA). However, as States exhaust these funds, and as State budget gaps persist, many will be forced to scale back childcare assistance for families unless additional Federal funding is provided. Already, a number of States and communities have begun to cut back on childcare assistance”. . . .

—California’s governor is proposing to eliminate childcare assistance for 11- and 12-year-olds, lower the income eligibility limit for childcare assistance from 75 percent of State median income to 60 percent of State median income, and reduce reimbursement rates to childcare providers serving children receiving childcare assistance—which would likely result in families being forced to make up the difference.

—Florida’s waiting list for childcare assistance increased from approximately 67,000 children in early 2010 to 89,000 children as of December 2010.

—Maryland will place all families who apply for childcare assistance after February 28, 2011 on a waiting list.

—North Carolina’s waiting list for childcare assistance increased from approximately 37,900 children in early 2010 to nearly 45,700 children in December 2010.

⁴The letter includes support for Head Start and Early Head Start.

⁵*Additional Childcare Funding Essential to Prevent State Cuts* from the National Women’s Law Center. Retrieved April 8, 2011, from <http://www.nwlc.org/resource/additional-child-care-funding-essential-prevent-state-cuts>.

—New York City's mayor is proposing to cut childcare assistance to more than 16,600 children.

YWCA childcare programs in these States, and many more States across the country, are already being impacted by State cutbacks. These cutbacks will be amplified, and their impacts will be amplified, if CCDBG funding does not continue at the levels requested by the President's fiscal year 2012 budget request. For the YWCA, this means our associations will have to cut vital programs and services, reduce the number of families served, and possibly even close YWCA facilities leaving many women and families without affordable, quality, childcare to allow them to work and provide their children a safe, developmentally appropriate environment.

The YWCA recognizes these are unique times in our Nation's history and we agree that our Nation must address its deficit and debt. Yet, the YWCA believes strongly that investments in childcare and early education programs are wise uses of Federal funds that provide substantial returns to our Nation. Childcare and early education programs help not only our Nation's current workforce, but also help prepare the next generation our Nation's children. On behalf of YWCAs nationwide and the many women, children and families we serve, we look to you for a continued commitment to women and families through the provision of essential childcare resources. That is why we respectfully ask you to support the President's fiscal year 2012 budget request for \$1.3 billion in additional funding for CCDBG. Thank you once again for the opportunity to provide testimony in support of childcare services, and CCDBG especially, to your Subcommittee. Your attention and assistance are greatly appreciated.